THE WHITE HOUSE CONFERENCE ON HANDICAPPED INDIVIDUALS

VOLUME ONE:
AWARENESS PAPERS

HV1775
W587
Vol. I

M.C. MIGEL MEMORIAL LIBRARY
American Foundation for the Blind
15 West 16th Street, New York, New York
10011

THE WHITE HOUSE CONFERENCE ON HANDICAPPED INDIVIDUALS

VOLUME ONE:

AWARENESS PAPERS

Washington, D.C.
May 23-27, 1977

HV1775
W587
Vol. I
Copy one

TO ALL DELEGATES AND OBSERVERS

The materials in this White House Conference on Handicapped Individuals document represent a compilation of information concerning the aspirations, abilities and problems of physically and mentally disabled Americans of all ages, races, beliefs, gender, educational levels, income brackets and ethnic origins.

It is especially remarkable in that it was assembled in an unusually short period of time. To attempt to present a cohesive and comprehensive document from many sources is indeed difficult, and required the dedication of many persons.

The heart of this material is the library of Awareness Papers. Early in the White House Conference planning process, we had to organize major areas of concern, topical sub-categories of interest, and recruit experts in each field to provide a mechanism for reaching a common understanding of the various problems facing individuals with handicaps.

The challenge to the author/editors was to make the papers readable, thought provoking and capable of inciting discussion among Conference delegates. In addition, they were designed to help surface issues and elicit alternative solutions.

We hope that you, as a concerned White House Conference delegate, will take time to read the Awareness Papers as an important part of your preparation for this crucial National Conference.

Finally, may we all work together to make this the definitive Conference on the needs and potentials of all disabled Americans so that our Third Century of existence, as a nation, will guarantee full opportunity for independent and dignified participation in whatever daily activity we may encounter as disabled citizens.

Dr. Henry Viscardi, Jr.
Chairman, National Planning and Advisory Council

Jack F. Smith
Executive Director

Digitized by the Internet Archive
in 2010 with funding from
Lyrasis Members and Sloan Foundation

http://www.archive.org/details/whitehouseconfer01whit

CONFERENCE OVERVIEW

The mission of the White House Conference on Handicapped Individuals is comprised of three goals:

to provide a national assessment of problems and potentials of individuals with mental or physical handicaps;

to generate a national awareness of these problems and potentials; and

to make recommendations to the President and Congress which, if implemented, will enable individuals with handicaps to live their lives independently, with dignity, and with full participation in community life to the greatest degree possible.

The White House Conference on Handicapped Individuals was authorized with the passage of Public Law 93-516. The chief Congressional sponsors of this legislation were Senators Harrison Williams, Jennings Randolph and Thomas Stafford; also, Representatives John Brademas and Albert Quie. Title III of that law stated that there were some "seven million children and at least twenty-eight million adults with mental or physical handicaps, and that "it is of critical importance to this Nation that equality of opportunity equal access to all aspects of society and equal rights guaranteed by the Constitution of the United States be provided to all individuals with handicaps."

Toward that end, the President was authorized to call a White House Conference which would "develop recommendations and stimulate a national assessment of problems and solutions to such problems facing individuals with handicaps." Announcement of the Conference was made by the President on November 22, 1975 with the date for the National Conference set for December 1976 and then changed to May 1977.

The result of the White House Conference should be a new advancement by and for handicapped individuals, with this movement picking up momentum following the publishing of recommendations. If the recommendations and implementation plan are to be instrumental in generating that momentum, they must emerge as a consensus from a broad base of support. The purpose of the National Conference is to become a focal point for such a consensus.

For the National Conference to be successful, it is especially critical that the energies and ideas of handicapped people be engaged. At least 50 percent of the State delegates to the White House Conference will be handicapped, and 25 percent parents or guardians of handicapped individuals. Professionals who provide services and others from business, labor and government who are interested in the problems of the handicapped will attend.

The criterion for a successful Conference also includes the opportunity for free participation by the delegates. At the same time, the deliberations must focus on key issues, through the use of a comprehensive multiple media program.

To get the kind of involvement necessary to generate national awareness foreseen in the Conference goals, we will enlist every active part in the Conference activities during the National Conference. Members of Congress and their staffs will also be involved to maintain their support.

With sufficient administrative support, we believe this strategy can be implemented and will be successful in creating the climate and the specific steps necessary to enable handicapped individuals to realize their potentials as contributors to American life.

The final White House Conference report to the President will offer very specific solutions to problems facing individuals with handicaps, and an implementation plan to guide the President and Congress in their collective efforts to ensure maximum follow-up of Conference recommendations.

THE WHITE HOUSE CONFERENCE ON HANDICAPPED INDIVIDUALS

Staff

Jack F. Smith
Executive Director

Joe Magnino
Executive Special Assistant

George Conn
Special Assistant

Alfred Emery
Special Assistant

Paul R. Ackerman
Director of Planning and Evaluation
Planning Chief for Educational Concerns

Miriam W. Rappaport
Special Assistant to Director
of Planning and Evaluation

William Shepherd
Planning Chief for Consumer Affairs

Sherri Ash
Planning Chief for Social Concerns

Dennis Wyant
Planning Chief for Economic Concerns

Rosemarie Brooks
Planning Chief for Special Concerns

Margaret Parsons
Planning Chief for Health Concerns
Planning Specialist for Consumer Affairs

Louis Rigdon
Planning Specialist for Social Concerns
Author/Editor: Civil Rights Awareness Paper

Odessa Woods
Planning Chief for Special Populations

Marilynne Tilson
Planning Chief for Cultural Affairs

James P. Gelatt
Consulting Editor

TABLE OF CONTENTS

HEALTH CONCERNS *Page*

Research
J. K. Weston 1

Application of Technology to Handicapping Conditions and for Handicapped Individuals
Part A: Application of Technology to Handicapping Conditions and for Handicapped Individuals
W. R. Ayers 15
Part B: Rehabilitation Engineering
M. C. Parsons & M. W. Rappaport 35

Early Diagnosis and Early Intervention
D. Whitehouse 45

Prevention of Disease and Disability
W. F. Malone 61

Treatment
C. A. Swinyard et. al. 73

SOCIAL CONCERNS

Attitudes of the General Public Toward Handicapped Individuals
H. E. Yuker 89

Psychological Adjustment of Handicapped Individuals and Their Families
J. L. Bardach 107

Recreation
D. C. Park 119

Participation in Cultural Activities
V. Cassiano 133

Architectural Accessibility
R. L. Mace 147

Transportation Accessibility
H. F. Goodkin 167

Communication: Techniques, Systems, Devices
P. A. Scherer 187

ECONOMIC CONCERNS

Employment
R. T. Sale 205

Economic Concerns of Handicapped Individuals
M. Berkowitz et. al. 217

EDUCATIONAL CONCERNS

Full Educational Opportunities for Handicapped Individuals
Council for Exceptional Children 247

SPECIAL CONCERNS

Problems of the Severely and Multiply Handicapped
F. Fay 287

Community and Residential Based Housing
L. Frieden 317

Service Delivery Systems
D. Stedman 349

Service Delivery Systems
C. W. Hoehne (P. Hoffman, Ed.) 369

Civil Rights and Addendum
L. T. Rigdon 393

Unique Problems of Handicapped Minorities
R. Wakabayaski et. al. 425

Unique Problems of Disabled Veterans
J. A. Maye 449

Unique Problems of the Handicapped Aging
D. A. Davis & O. I. Onyemelukwe 457

The Awareness Papers contained in this volume were prepared by subject-matter experts to serve as one resource for discussions leading to solutions of problems facing all individuals with mental and physical handicaps. These Papers were not intended to be all-inclusive, but were designed to stimulate discussions. They reflect *only* the attitudes, opinions and research of the authors/editors, not the White House Conference Staff.

RESEARCH

Awareness Paper Prepared By

Jean K. Weston, Ph.D., M.D.
Adjunct Professor of Clinical Engineering
George Washington University
School of Medicine
Washington, D.C.

ACKNOWLEDGMENT

The White House Conference on Handicapped Individuals wishes to thank the following individuals who contributed significantly to this document:

Samuel J. Keith, M.D.
Assistant Chief, Center for Studies of Schizophrenia
National Institute of Mental Health
Rockville, Maryland

Murray M. Kappelman, M.D.
Professor of Pediatrics and
Associate Dean for Student Affairs and Medical Education
University of Maryland School of Medicine
655 W. Baltimore Street
Baltimore, Maryland

TABLE OF CONTENTS

	Page
Introduction	5
State-of-the-Art of Research Dealing with the Handicapped	
General Commentary	8
Existing Research Establishment with Particular Relationship to the National Institutes of Health	9
Research Primarily Devoted to the Nervous System	
General Commentary	10
Potential Causes of Injury to the Nervous System	
Ongoing Nervous System Research	11
Mental Retardation	12
Mental Illness and Disability	12
Recommendations	12

INTRODUCTION

Definition

Who is handicapped? What kinds of handicapping conditions exist? Most people, when asked these questions, would point to the more obvious and severe physical and mental handicaps such as blindness, deafness, stroke, and other debilitating conditions. Upon further reflection, they would identify other handicaps where the individual exhibits some degree of physical helplessness and is dependent upon others for his survival and well being.

A more inclusive—possibly too inclusive—definition would be to consider anyone handicapped who, through injury, disease or any other cause, is unable to, or prevented from realizing his full potential in our society.

With this latter definition in mind, it is clear that the numbers of handicapped individuals are infinitely larger than one would at first imagine. To stress this further, *all* of us are handicapped many times during our life cycles, at least for short periods of time following accidents, diseases or disturbing psychological reactions to our environment. As our bodily machinery deteriorates with age and use, *all* of us become prey to the associated degenerative diseases, especially cardiovascular, pulmonary, bone and joint, and neuromuscular; all of which, either separately or together, compromise the ability of the elderly to adapt to other than a nursing home or hospital environment. Some become almost *totally* handicapped. Not only is this a burdensome expense to society in terms of total health care delivery, but the associated quality of life for elderly handicapped individuals is such that none of us can or should contemplate it with equanimity. It is easier and less emotionally unsettling to ignore it—which most of us do so far as possible most of the time.

Problem

How can society best and most expeditiously prevent, cure, and ameliorate all handicaps which afflict our citizens? To the degree that this can be done, there should be fewer and fewer handicapped citizens who are not fully productive, self-supporting and a part of the mainstream of society. A large segment of society has but relatively recently embraced the concept that all people have a "right" to good health and the government, via legislation, has committed substantial resources to fulfill that right. It appears that the aim is to solve the problem of all handicapped.

Solution of the Problem

Looking to the future—and in view of some facets of the total problem of the handicapped having been solved in the recent past, poliomyelitis, for example—the importance of scientific research must loom ever larger in any plan designed to make inroads on the problems presented by the handicapped. Because of its proven performance in nearly all aspects of our existence, research is looked upon by our society as the basis for the solution to many of our problems.

Definition of Research

Research is anything which produces and develops knowledge. "Pure" research or "basic" research observes, develops, and studies facts and draws inferences or conclusions from such studies. On such bases, hypotheses are developed and subjected to experimental attack, ideally through application of the "scientific method" and the conduct of experiments where but one variable at a time is carefully examined. "Applied" research or "targeted" research involves the use of scientific methodology directed at solving a specific problem, for example, the development of a poliomyelitis vaccine.

It should be clear the foregoing definitions include both "bench" research—where inanimate objects as well as any and all living forms except man may be involved as the research subject, and "clinical" research dealing directly with the study of man and using man, himself, as the research subject. "Clinical" research is generally considered to be much more difficult and much more expensive than "bench" research, primarily because man is a difficult experimental subject to handle and quantify, and especially since ethical and moral strictures must always be considered. The terms "retrospective" and "prospective" research should also be clarified. Retrospective research involves looking back historically at the available recorded data and drawing supportable inferences and conclusions therefrom. Researchers usually view most retrospective study results with caution and conservatism.

"Prospective" research frequently stems from retrospective studies. Here a rigorous research plan or protocol is carefully laid out, frequently with the aid of statisticians (who largely scorn retrospective studies). Indeed, if the plan is properly conceived and carried out, the "prospective" research route is the way to go to be reasonably certain that the most valid data from the smallest number of subjects will become available most rapidly.

It should be noted that the numbers of high quality, prospective clinical research studies on record are not yet large. However, it should also be noted that prospective research methodology has improved greatly in the past 20 years. Dependable data and information can be derived most efficiently by the prospective route with fewer humans involved as research subjects.

The important, well-known and widely appreciated facts are that many health problems have been solved to variable degrees by a proper and effective mix of basic and applied research. They are, in practice, mutually complementary, not antagonistic or mutually exclusive. Poliomyelitis is perhaps the most striking and well known health problem solved in modern times by a mix of the two kinds of research.

Historical View of Research as it Relates to a Handicapping Disease—Poliomyelitis

For several generations poliomyelitis was recognized descriptively, its cause unknown, with some ameliorative but no curative treatment being available.

Until biomedical researchers, both basic and applied, recognized bacteria and viruses as being related to disease; could identify the various kinds of viruses; and had devised means to propagate them in pure line strains, that is, grow them under carefully controlled conditions so they would not be mixed with other viruses; little progress could be made in diagnosis, ameliorative therapy, cure, or prevention. Nevertheless, applied researchers during this period did produce useful, life-preserving methodologies, such as the "iron lung" so essential in maintaining life in those afflicted because a virus had attacked and destroyed the nerve cell centers in the brain and spinal cord which control breathing.

Until animal models of the disease could be discovered and developed so that the disease could be studied scientifically under controlled conditions, progress was slow and laborious. In short, once the cause was established, further research, both basic and applied, was needed to develop appropriate methodologies that promised to be effective in man either on (1) a risk-benefit basis (the potential harm of the therapy developed for the total group of patients needing that therapy was substantially less than the overall benefit to the great majority of patients likely to receive it), or (2) a cost-effective basis (the cost of developing an effective counter to the disease overbalanced the cost of letting the disease run unchecked), or (3) both bases.

Finally, when a certain stage had been reached by research studies, mostly on animals, and a thoughtful consideration and integration of the total available human information carried out, at that point in time only could a human trial provide a definitive answer. This involved education, decision making, and the cooperative support of leaders in science, medicine, industry, and government; together with public health education to enlist public cooperation and understanding. The rest of the story is well known. The field trials were successfully mounted and carried out; the original vaccine proved effective; widespread immunization programs were subsequently carried out over several years; improved live virus vaccines were developed; and the disease was eradicated for all practical purposes. But the virus continues to exist, so immunization and public health education must continue to maintain the disease under control. If this be done, human handicaps from this source, at least, are very unlikely to develop. All this research and development was costly, but the benefits have been well worth the cost involved.

It should be stressed that research on poliomyelitis viruses continues because research has shown that microorganisms can change or mutate and thereby become resistant to available therapies. It should also be stressed that much of the research information developed in the poliomyelitis area was utilizable in studying and countering other virus diseases, notably measles.

It is especially true of basic research that one cannot predict what continuing research—in an area where a massive breakthrough has occurred, such as for poliomyelitis—may accomplish in the future to aid the handicapped.

A very different, but no less important, kind of currently ongoing research also deals with the pediatric handicapped. Psycholinguistics addresses itself effectively to the psychological factors underlying a child's development of

speech and how these can be manipulated to develop a more favorable climate so the child can learn to speak better and more rapidly.

Furthermore, research continues on many well-recognized and treatable diseases to better understand the full range of their effects when undiagnosed or misdiagnosed and not properly treated. Thus it is known that Hemophiliaes influenzae-caused meningitis, which untreated results in severe handicapping neurological sequelae among those who survive. Finally, a methodology called amniocentesis, which provides a sample of cells from the embryo *in utero,* can tell the physician of possible health handicaps. The foregoing all stress the pediatric area. It should be clear that effective research in the pediatric area is most likely to be among the most cost-effective and risk-beneficial, and therefore warrants its full share of the research budget. Research productivity here is likely to remove or reduce handicaps early in life.

Another example of ongoing research in the pediatric area, but with practical extensions to the adult area, is that regarding lead poisoning. The many publications on lead poisoning in children; the source of the lead in the paint on the crib, in the plaster or on the furniture, all of which small children chew, are well known; and lead-based paint is fading from the picture as a source of poison causing severe central nervous system dysfunction. In a recent issue of the Journal of American Medical Association, an interesting piece of clinical research, reminiscent of Sherlock Holmes, demonstrated that cocktail glasses with lead-based, painted scenes on them apparently caused detectable lead poisoning in adults, but *only* when washed in a dishwasher where the strong detergent removed the surface coating, allowing the lead base to be dissolved into the cocktail.

Basic Concepts Relating to Research Likely to Benefit the Handicapped

A. Time-Frame

It is important to understand that research progress is necessarily time-frame dependent. Until the knowledge time-frame existed where the causative agent of poliomyelitis had been scientifically and conclusively demonstrated, little further progress could have been made regardless of the amount of financing and/or the human expertise that might have been deployed.

B. Research Competence

Research progress of any sort, all other things being equal, is also dependent upon sufficient numbers of trained research personnel provided with appropriate facilities and support. Being human, highly motivated, and desiring to visualize accomplishment from their efforts, researchers tend to enter those fields where interesting scientific findings are emerging, especially those having implications for practical applications.

C. Methodology

Another ingredient for successful research is the availability of sophisticated methods. Without the availability of monkey safety test procedures dependent upon the known histopathological characteristics of poliomyelitis in the rhesus monkey and the known techniques for handling the monkey in large numbers in the laboratory, the development of the vaccine could have been materially delayed. This can also be said of the methodology developed for growing polio virus in quantity on monkey kidney tissue culture.

D. Financial Support

Little progress would have been made on polio research had not appropriate funding been available over a period of many years, or had it not been expended relatively rapidly and liberally when the state of the art so warranted. Interestingly, the reason for this was the tremendous success of the March of Dimes in collecting public contributions. Funds were obtained in sufficient amounts to support those research activities which seemed pertinent and necessary to carry out the March of Dimes' objective.

It should be kept in mind that this development was largely supported by public donations being diverted to research in universities. The pharmaceutical industry also became involved since it had expertise in vaccine production and testing. This occurred before the day of large government appropriations for support of biomedical research.

Undoubtedly some funding supports non-productive research. Not all research produces the objective delineated in the time-frame involved, but who's to know how productive it might be in some subsequent time-frame? This is particularly true of basic research which is aimed at developing knowledge.

It is unfortunate that the public has somehow been led to believe that if only adequate sums of money are made available to researchers, any research objective, such as the cure of cancer, can be attained. Nothing could be further from the truth. Such guarantees should neither be made

nor implied.In short, while money is essential to develop the trained and motivated personnel and the methodologies necessary to make for research progress in any defined research area, it must be made continuously available so that the methodologies and the personnel may be optimally productive, particularly in an appropriate timeframe. *Money alone cannot insure research productivity.* When attempts are made to legislate progress by appropriating substantial sums of money for stated research objectives before the appropriate time frame warrants, the money is distributed, but little progress is likely to be made.

E. Interdisciplinary Research

Although the virtues of interdisciplinary research, especially in the applied area where an objective is clearly visible and outlined, seem reasonably well appreciated today, the many areas where real research progress has been made faster by interdisciplinary research and have benefited the handicapped deserve recognition. It should be sufficient to refer to the development of relatively safe and effective drug products by the pharmaceutical industry's multidisciplinary team "target" research.

Such team research, aimed at a specific goal, intermixed basic and applied research. Examples are: (1) A variety of vaccines and antibiotics controlling many handicapping infections, and (2) the phenothiazines that permit many mental patients to return home from mental institutions and become more nearly normal members of their families and communities and that spark more biochemical research dealing with brain functioning. It is noteworthy that to effectively utilize the psychoactive drugs in the minimally brain damaged child, to minimize the handicap, required a coordinated team effort among physicians, teachers, psychologists and patients.

STATE-OF-THE-ART OF RESEARCH DEALING WITH THE HANDICAPPED

General Commentary

Under the broad definition of handicap previously noted, basic research dealing with a multiplicity of human health problems has received generous public financial support since the late 1940's. The story of the sequential establishment of the National Institutes of Health recapitulates the increased awareness of the degrees to which different types of diseases resulted in human handicaps. The sequential story of the varying appropriations to each of the Institutes is another measure of the changing degrees of such awareness, interest and emphasis in ameliorating handicaps. It is difficult to measure how the public identifies research funding activity as a force to ameliorate or eradicate specific human handicaps, but surely many of the educational pamphlets, papers and comments from researchers and from the Institutes stress the importance of basic research in treating, curing, or preventing many human handicaps.

In recent years, the public has expressed disappointment and/or dissatisfaction with the rate at which demonstrable benefits to the handicapped have resulted from basic research. There has been articulated a desire for more practical, applied research that would be more likely to result in immediate benefits to the handicapped. It is indeed unrealistic of the public or of the government to expect more research productivity, either basic or applied, when less money is appropriated for ongoing programs and when the monies made available have their purchasing power substantially diminished by continually burgeoning inflation.

Furthermore, one detects an increasing climate of anti-intellectualism related to basic research and scientific workers at the bench. This is disturbing to research scientists and it should be more disturbing to leaders in universities, government, medicine, and industry and to the public. This climate may inhibit some individuals from choosing research as a career.

Another disturbing aspect, when one comtemplates the research picture as it involves the handicapped, is public antagonism to having clinical research carried out on humans, especially on children, potentially pregnant women, prisoners, and on persons living in the Third World countries. Despite the fact that we have learned how to conduct productive, controlled, relatively safe human research requiring fewer subjects, fewer competent clinicians want to become involved, partly because of the added paper work involved, but more perhaps because they will be viewed negatively by colleagues and the public and they fear liability. One cannot help but wonder whether this relatively recent and disturbing facet of human research would not have substantially delayed the appearance of the polio vaccine.

It appears then, in summary, that research has been supported for nearly twenty-five years in

increasing amounts until recently when there has been reluctance to substantially increase appropriations even to the degree necessary to balance the decreased purchasing power of the research dollar. The large-scale research programs have produced substantial amounts of useful basic knowledge, highly sophisticated methodologies, and large numbers of highly-trained researchers. We must see how these results can be transferred to prevent and ameliorate handicapping conditions.

Existing Research Establishment with Particular Relationship to the National Institutes of Health

The emergence of the National Institutes of Health (NIH) as the leading health research activity is a significant accomplishment, both in terms of the NIH research workers and the insights and abilities of the extra-governmental research establishment which has worked closely with NIH. It is no less a creditable accomplishment of those governmental and community leaders who themselves developed an awareness and insight into what scientific research was and what it might do for the handicapped, given adequate financial support and competent leaders.

There can be no question that, through NIH leadership and continuing support, large amounts of basic knowledge have been derived. Much of this knowledge has been published and is freely available to all. Some information may be classified or not yet ready for publication; some may be in the files of the individual researchers and have limited immediate availability.

Among the published material may be many facts and concepts that could spark interest in applied research programs to prevent and ameliorate some handicapping conditions. Researchers will have to review, analyze, understand, and derive ideas for future applied research that is most likely to be practically productive to the handicapped.

The broad-scale of NIH programs can be exemplified by some specific activities. It is not possible to assign dollar values to research on the handicapped conducted by the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) because almost all of the $130 million research budget is, to one degree or another, related to handicapping disorders. It is estimated that 20% of this budget is targeted directly at specific problems of neurologically handicapped individuals. Research programs are concerned with such problems as paralysis resulting from head and spinal cord injuries, childhood crippling from muscular dystrophy, disturbances from sclerosing disorders, communications impairment, and senile dementia.

One large-scale NINCDS project deals with cerebral palsy, mental retardation, and sensory disorders of infancy and childhood. In the last 20 years data have been collected on approximately 58,000 pregnancies and the resultant offsprings have been studied through age eight. Diseases and complications during pregnancies that contribute to brain damage and handicapping neurological disorders in offsprings are being identified. Another important research priority of NINCDS is concerned with developing and evaluating diagnostic and treatment techniques for hearing, speech, and learning disorders. Neuromuscular prosthetics are being developed for bladder control and fine hand movements. In addition to basic and clinical research on causes of stroke and its management in the acute phase, NINCDS is supporting research efforts in the rehabilitation of stroke victims.

The National Institute of Child Health and Human Development (NICHHD) supports research on mental retardation, developmental and cognitive disabilities, congenital defects that result in structural and metabolic handicaps, suboptimal mental and physical growth, and other problems that can lead to handicapping conditions. Some of the areas being researched by NICHHD include genetic diseases; perinatal risks; and social, economic, and family environmental factors in disease etiology.

Other institutes of the National Institutes of Health are also concerned with handicapping conditions even though their research plans and proposals may not specifically say so. But their basic and applied research often results in approaches or materials that prevent or ameliorate handicapping conditions. The National Cancer Institute, for example, has spearheaded both programs to promote early diagnosis leading to early cure and studies to establish the role of chemical agents, surgery, and radiation in the control and cure of certain cancers. Furthermore, NCI has developed educational programs to help citizens at all levels identify and seek treatment and better understand the problems resulting from cancer. A number and variety of public supported organizations, at the national, regional and local levels, have worked cooperatively in both cancer research and educational endeavors.

Some have received support from the National Cancer Institute or from private foundations and/or public solicitations. Such groups have done or supported a large amount of basic research on nearly every aspect of cell biology which has led to better understanding of abnormal cells and how they can be modified. Examples of such organizations are the American Cancer Society, the Sloan-Kettering Institute for Cancer Research in New York City, and the Detroit Cancer Institute.

The National Heart and Lung Institute has supported many research activities on cardiovascular diseases. The relationship of hypertension to the development of cardiovascular handicaps has always been a high priority research activity of this Institute. In the cardiovascular area, too, a variety of publicly supported organizations are active at local, regional, and national levels.

Actually, due to their extramural research programs which place all of them into contact with most health research efforts world-wide, a poll of each of the National Institutes of Health would be a most effective way to obtain opinions on research projects of greatest relevance and interest to researchers working on handicapping conditions.

RESEARCH PRIMARILY DEVOTED TO THE NERVOUS SYSTEM

General Commentary

Despite the fact that poliomyelitis is a viral infection, communicable from man to man and from monkey to man and particularly prone to attack children, its manifestations are expressed as infinitely variable deficits of the human motor apparatus as well as, in some patients, other parts of the nervous system. Obviously, with such deficits there are apt to be psychological problems associated. All require a variable degree of medical attention and continuing, close domiciliary care, education, and treatment. Perhaps the most severe manifestations are quadriplegia and loss of function of the muscles controlling respiration. In addition, the likelihood of mental depression and progressive deterioration is great. Obviously such patients require medical care throughout the balance of their lives, probably in a hospital or nursing home, and such care is tremendously expensive and far beyond the means of any but the wealthy. The various deficits of the less severely handicapped and the cost of their continuing care, education, and rehabilitation will also be very expensive. Such costs can financially cripple most families. By exhausting the total family assets, a handicap to one member can indirectly handicap other family members in good physical health and make it impossible for them to develop their potential.

Their healthy psychosocial development can also be grossly compromised. Thus, one handicapped family member can impact adversely on other members of the family. This is a further net loss to society.

With the foregoing in mind, one of the most helpful, immediate contributions society can make is to assume much of the medical care and rehabilitation costs involved. To some degree, society does. The March of Dimes program realized this early and helped to defray such costs to many afflicted persons. Our government is only now seriously considering passing legislation designed to benefit such catastrophically expensive handicaps.

While the general purpose and function of the nervous system (together with the endocrine system) as the integrator of all body functions has been generally understood for many years, the complexities involved are only now being reasonably well recognized. Interdisciplinary research has cast much light on the underlying biochemical activities involved, the relationship of genetics to enzyme deficiencies underlying defective brain functioning, genetic defects, congenital metabolic abnormalities and birth defects and, finally, a better appreciation of the mosaic of neuroendocrine functioning. All of these have more clearly appeared in the forefront of our understanding because of recent research. Research on some psychiatric handicaps, among the most numerous and costly handicapping conditions involving malfunctioning of the nervous system, is beginning to yield interesting biochemical leads which, if exploited effectively, may markedly ameliorate, cure, or prevent certain psychoses.

Man has highly developed special senses of vision and hearing, the special senses that relate him to things at variable distances in his environment, whose proper functioning are most important for effective, normal brain functioning and total effective adjustment to a constantly changing environment. This is why blindness or deafness from any cause is so severely handicapping to the individual, especially if such limitations occur later in life when individuals have

learned to depend on such senses to adjust to their environment.

Because man, supported against the forces of gravity on two relatively spindly legs, is, except when sitting or lying, in a state of unstable equilibrium, the refinement of his motor coordination must be superb.

Furthermore, the parts of the body involved in motor coordination are at substantial distances from each other and from the brain and spinal cord. These parts are all interrelated by nerve fibers, the outgrowths of nerve cells located mainly within reasonably well charted areas of the brain or spinal cord or within even better charted recognizable nerves. These nerve fibers connect the brain and spinal cord to the specific kinds of cells in specific locations throughout the body and must function in an interrelated manner to adjust the individual to his environment, the gland cells and the muscle cells. Patterned discharges of nerve impulses over this nerve fiber network largely accomplish the desired, constantly changing, interrelated functions of the human body.

Nerve fibers in the spinal cord or brain do not regenerate once they are disrupted, whereas those in the nerves themselves do. This has obvious implications for the relative permanence of handicaps resulting from damage to the brain and spinal cord. This is why a cure for poliomyelitis was realized as an impossibility and the research scales were tipped to find a vaccine to prevent the central nervous system damage.

The National Institute of Neurological and Communicative Disorders and Stroke has long recognized the problem of non-regeneration of nerve fibers within the central nervous system as basic to non-repairable central nervous system damage.

Potential Causes of Injury to the Nervous System

The poliomyelitis virus, for whatever selective reason, kills specific nerve cells in the spinal cord which control the right arm and can result in a complete paralysis that might never significantly improve. Alternatively, a growing tumor, an aneurysmic swelling of a blood vessel, or a knife thrust or bullet that would disrupt the larger nerves in the neck and shoulder region, for example, could also paralyze the right arm. Here, however, prompt diagnosis and appropriate surgical treatment, together with appropriate rehabilitative therapy, could restore the arm to normal or near-normal function. Research productivity results in more complete cures of such nerve damage all over the body. Furthermore, a bacterial infection in the blood stream could also differentially kill the nerve cell pool controlling the right arm and evidence results similar to poliomyelitis. Rapid diagnosis and appropriate antibiotic therapy, both products of research, today help keep harm from infections to a minimum. A variety of other causative agents, pressure, chemical agents, a knife or a bullet, could disrupt other groups of nerve fibers or nerve cell pools in the upper spinal cord or the brain with similar effects on the right arm.

Hereditary defects could result in maldevelopment of the arms or a portion of them; or such defects could result from chemicals interfering with the orderly development of the human embryo, as thalidomide demonstrated. The positive value of thalidomide as a sedative in other than pregnant women is well known. Recent research suggests that it is also valuable in treating leprosy under some circumstances.

Chemical and physical agents as well as infections and congenital or genetic abnormalities can cause equally serious and varied handicaps to the individual. With such varied etiologies, it is clear that wide support of research is necessary. It should be equally obvious that both basic and applied research follow many pathways to improve our knowledge and understanding of nervous system structure and function and result in techniques and materials that benefit the handicapped. It is the research results in the nervous system field that should be intensively studied; and nervous system research should receive more funding, especially in the applied area, to be of practical benefit to the handicapped.

Ongoing Nervous System Research

While specific National Institutes of Health focus their attention on areas related to the nervous system, it is likely that all the Institutes involve themselves to some degree with the nervous system in their research activities. Some activities of NINCDS have been noted. Recently, NINCDS sponsored a Paraplegia Workshop to consider problems peculiar to spinal cord injury, expecially bowel complications; bladder function control; and the prevention, care, and treatment of bed sores. This workshop suggested the

establishment of facilities for paraplegics at existing hospital centers.*

Mental Retardation

Another important research area supported by NIH deals with all aspects of mental retardation, ranging from minimal brain dysfunction in children to a variety of senile brain dysfunctions. The Institutes involved and interested in the learning disabilities of children are cooperating among themselves, with State Departments of Special Education, and with interested publicly supported agencies, such as the Association for Children with Learning Disabilities, to carry out research studies. Basic research on the nervous system will lead to applied research findings that can be of practical importance to handicapped individuals. Research is desperately needed on attention, perception and memory.

Research in the field of mental retardation was addressed by the President's Committee on Mental Retardation in its March 1976, *Report to the President.* The most severe forms of mental retardation result from disorders of the nervous system involving the brain and usually occur before birth because of genetic anomalies or injury to the fetus. Man's knowledge of genetics and environmental hazards is still limited, but enough is known to provide a basis for markedly reducing the number of babies born with defective mental and physical development.

Research is needed to advance knowledge in the field of mental retardation. Vigorous action must be taken to implement research findings to reduce the incidence of mental retardation. Specifically, where the causes of mental retardation are understood, research should focus on prevention, early identification, and amelioration. Research is needed on the behavioral and chemical environments, as well as techniques and procedures. A major effort is needed to coordinate research findings. There is also a need to make the public and professionals aware of available information centers that identify current research and maintain information on completed research related to prevention of mental retardation.

The Report of the President's Task Force on the Mentally Handicapped, entitled "Action Against Mental Disability," dated September 1970, stated that the savings effected by therapeutic and preventive measures discovered through research soon offset the research expenditures. When one serious case of mental retardation is prevented, the direct savings in terms of the cost of lifetime care are more than $100,000. Such research can be truly cost-effective.

Mental Illness and Disability

Research into the causes of mental illness identify structural (anatomical) changes in the brain in only a minority of disorders, those associated with infections, intoxicants, tumors, vascular disease, and the aging process. Pharmacological research has made great strides in ameliorating the effects of mental illness. The use of the phenothiazines was one of the earliest steps forward. More recently the effectiveness of lithium has become well established.

In spite of great deficiencies in scientific knowledge, the last 30 years have seen a revolution in the methods and effects of psychiatric treatment. A more humane and liberal approach not only has led to earlier and consequently more effective treatment, but also has modified the forms of mental illness and resulted in fewer handicapping conditions.

In no other field of health is an understanding of the interplay of heredity, development and environment so necessary. Social and environmental deprivation play a crucial part in the origin and continuation of many forms of mental disability.

There are many specific requirements for research in the mental health field, and the National Institute of Mental Health is constantly supporting research in many areas including the causes of several types of mental disability. One area where more attention is required is that of psychoneurotic disorders.

RECOMMENDATIONS

1. Financial support for research affecting the handicapped must be increased, at the least to compensate for the reduced purchasing power of the research dollar caused by inflation. Funds for basic research should not be neglected because of the increased demand for research funding. In addition, increased flexible funding for promising applied research must be made readily available.

*Spinal Cord Injury. Hope Through Research, DHEW Publication #(NIH) 72–160, PHS Publication, Health Information Series #143.

2. Basic and applied research results should be reviewed for information, procedures, and materials applicable to handicapping conditions.

3. Regional centers for research on handicapping conditions should be set up at existing government or private hospitals that have care and rehabilitation facilities for the handicapped. Further, persons with handicapping conditions who are patients in these hospitals should be trained to perform professional and auxiliary tasks in the research programs. They might be trained to actually design or conduct research, to review the literature for relevant materials, or to perform paraprofessional or clerical tasks connected with the research.

APPLICATION OF TECHNOLOGY AND REHABILITATION ENGINEERING

PART A: THE APPLICATION OF TECHNOLOGY TO HANDICAPPING CONDITIONS AND FOR HANDICAPPED INDIVIDUALS

Awareness Paper Prepared By

William R. Ayers, M.D.
Assistant Dean for Curriculum
Georgetown University
School of Medicine
Washington, D.C.

PART B: REHABILITATION ENGINEERING

Awareness Paper Prepared By

Margaret C. Parsons
Planning Chief
for Health Concerns
White House Conference Staff

Miriam W. Rappaport
Chief, Clearinghouse National Center
on Child Abuse and Neglect
Children's Bureau
Washington, D.C.

ACKNOWLEDGMENT

The White House Conference on Handicapped Individuals wishes to thank the following person who contributed significantly to this document:

Jerry D. Parham, Ph.D.
Director of Training
Research and Training Center in Mental Retardation
Texas Tech University
Lubbock, Texas 79409

PART A
TABLE OF CONTENTS

	Page
Introduction	19
Parameters of the Paper	19
Definitions	19
Delineation of the Problems	21
Historical Perspectives	21
Legislative Background	21
Scope of the Problem	21
Discussion of Problems	21
State of the Art	22
Technology—Its Generic Divisions	22
Health Services Delivery—A Conceptual Framework	23
Needs of the Handicapped	24
Strategy for Technologic Assessment	24
Examples of Existing Technology	26
Nontechnology	26
Half Way Technology	27
Decisive Technology	27
Promising Technology	28
The Future	29
Conclusions and Recommendations	29
Bibliography	30
Attachment	31

PART B

	Page
Technology: Past and Present	35
Technology: An Overview	35
Areas of Concern	36
Sweden's Model	36
Some Major Handicapping Conditions, Some Technological Advances, and Further Requirements	37
Visual Impairment	37
Hearing and Speech Impairment	37
Manipulation and Locomotion	38
Rehabilitation Engineering Centers	38
Producing the Optacon	39
RSA: Workshops and Technology Priorities	40
BEH Conferences	40
VA Efforts: A Total Concept	40
NASA: An Example of Technology Transfer	41
Technology Transfer and Production	41
Conclusions	42
Selected References	43

PART A
INTRODUCTION

Parameters of the Paper

The focus in this part of the paper is the boundary between technology and the handicapped. The emphasis is neither technology nor handicapped individuals; neither is it applied technology nor handicapping conditions. The use of the word "boundaries" is a deliberate one. "Interface," more commonly used, by definition in the metallurgic sciences is an *impregnable* division. Technology and the handicapped already have too many divisions that seem to be impregnable.

Rational discussion of technology and the handicapped demands the setting of limiting parameters. Both fields are so complex and in such a state of dynamic change that initial subdivision of the topics and exclusion of some potentially contributory but non-essential elements are required.

In order to generate a national awareness of the problems faced by individuals with physical or mental handicaps from the viewpoint of applied technology, we will review the philosophy of technologic development and the process of technology transfer using appropriate generic frameworks of reference and specific selected case studies. In order to stimulate a national assessment of technologic solutions to the problems faced by individuals with physical or mental handicaps we will propose a scheme for technologic assessment that views applied technology as a production function. Peculiar to such a maneuver is the ability to view technologic applications as both substitutive and additive to the other energies brought to bear on the total solution to the problems faced by the handicapped. The conclusions will be stated in a manner to aid in the development of recommendations for legislative and administrative actions that will allow individuals with handicaps to live their lives independently, with dignity, and with integration into community life. No attempt will be made to list all technologic applications to all facets of the lives of the handicapped; such is simply outside the scope of the paper.

Definitions

There are widespread differences regarding the definition of "handicap." HANDICAP has been defined by the Office for Handicapped Individuals, Department of Health, Education and Welfare, in terms of the person. Thus, a HANDICAPPED PERSON is one who because of a physical or mental disability is at a disadvantage in functioning in one or more major life activities. A *major* life activity is a relative definition. It is assumed that such activities are those that can reasonably be expected of a nonhandicapped person. *Handicap, impairment,* and *disability* are sometimes used interchangeably.[1] There are degrees of handicapping conditions: mild, moderate and severe, based on functional limitations. A list of handicapping conditions based on diagnostic categories is appended as Attachment A. The list is selective and includes those conditions that have a high prevalance rate or have received national recognition usually through the efforts of the public sector.

Many persons have several handicaps and are usually referred to as MULTIPLY HANDICAPPED. For the purpose of a review of technology applied to the handicapped, it is important to realize that there are no national incidence/prevalence studies of the multiply handicapped. However, the number of individuals with multiple handicaps is increasing because advances in medical science save the lives of high risk individuals, accident victims and disease victims who would have once died from these maladies.

An indication of the prevalence of multiply handicapped persons can be seen in Figure 1. The chronic causes of disability in non-institutionalized persons are seen in Figure 2 and in institutionalized persons in Figure 3.

In its broadest sense, TECHNOLOGY means the systematic application of scientific or other organized knowledge to practical tasks.[3] Its most important consequence is in forcing the division and subdivision of any such task into its component parts. Thus and only thus, can organized knowledge be brought to bear on change.

Failure to appreciate subtleties in the definitions cited and their implementation within our complex cultural and socioeconomic system has led to unsolved problems for technologists and the handicapped alike.

Function	No Other Handicap	Partial Handicap	Severa Handicap	Description of Severa Handicap
Ambulation	57.8	32.4	9.9	Able to take few steps with help or totally unable to walk
Upper limbs, gross motor control	57.5	34.2	8.2	Unable to hold large objects or complete lack of muscle control
Upper limbs, fine motor control	56.1	34.9	9.0	Minimal use of hands, cannot use eating utensils
Speech	45.1	33.4	21.5	Can possibly communicate needs or wants, but uses few or no words
Hearing	85.0	11.5	3.4	Functionally or totally deaf, hearing aid partial or no help
Vision	73.3	20.9	5.9	Minimally sighted (uncorrectable) or legally blind
Seizures (epilepsy, convulsions)	82.3	15.1	2.7	Severe seizures partially controlled or uncontrollable
Behavior, emotional disorders	58.1	35.7	6.3	Adjustment not possible in home environment, abnormal behavior, dangerous to self or others
Toilet training	77.5	10.2	12.3	Dependent on others, slightly toilet trained or not trained

Source: J. W. Conroy and K. E. Derr, Survey and Analysis of the Habilitation Status of the Mentally Retarded with Associated Handicapping Conditions (Washington, D. C.: U.S. HEW, SRS, 1971).

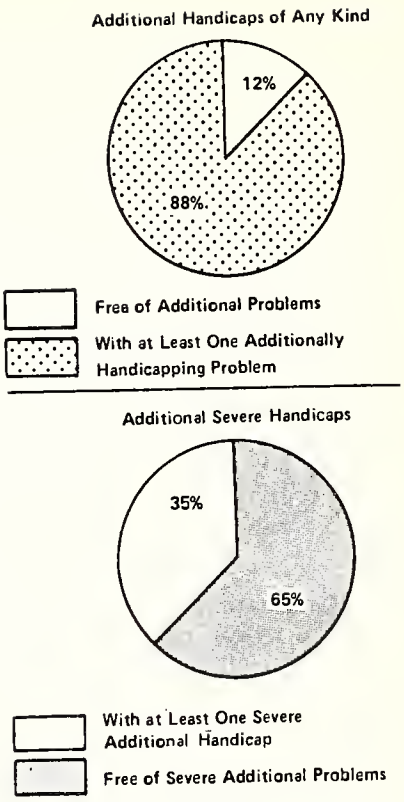
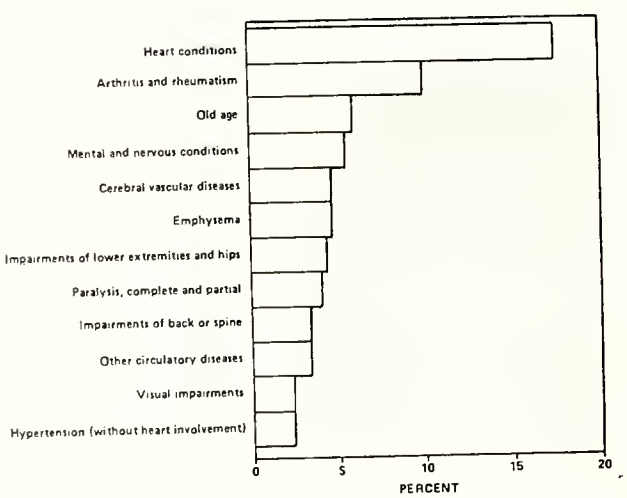


Figure 1. Prevalence of Associated Functional Handicaps in Mentally Retarded Persons by Percent



Source: Adapted from Executive Office of the President, Office of Management and Budget, Social Indicators--1973 (Washington, D.C.: U.S. GPO, 1973), p. 17.

Figure 2. All Noninstitutional Persons Unable to Carry on Major Activities, with Percent Due to Main Cause Chronic Condition, Two Year Average 1969-70

Institution	Number	Percent
Total	460,000	100.0
Psychiatric hospital or ward	299,000	65.0
Institution for mentally retarded	107,000	23.2
Chronic disease facility	54,000	11.7

"Chronic disease" facilities include all long-term care hospitals and wards and all schools or homes other than psychiatric institutions or facilities for the mentally retarded. The percentage distribution of disabled adults among the types of institutions included in this classification is shown below:

- Chronic disease (unspecified) 13.5
- Tuberculosis 27.4
- General 17.1
- Rehabilitation 11.1
- Homes and schools for the blind or deaf 7.3
- Extended care wards and geriatric hospitals 23.4

Source: Adapted from U.S. HEW, SSA, "Demographic Characteristics of Institutionalized Adults," *Social Security Survey of Institutionalized Adults: 1967*, Report No. 1, P. Frolich Washington, D.C.: Office of Research and Statistics, 1971), p. 2.

Figure 3. Institutionalized Adults, Age 18-64, 1967

DELINEATION OF THE PROBLEMS

Historical Perspectives for Technologic Application

A. *Legislative Background*

1. The Developmental Disabilities Services and Facilities Construction Act of 1970 (PL 91–517) significantly expanded the scope and purpose of the Mental Retardation Facilities Construction Act of 1963 (PL 88–164) by providing a combined formula and project grant program to states both for construction of facilities and the provision of services to persons with developmental disabilities.

2. The Rehabilitation Act of 1973 (PL 93–112) and Rehabilitation Amendments of 1974 (PL 93–516) improved and expanded the existing legislation to ensure greater flexibility in state administration of vocational rehabilitation services, established a new program for construction of rehabilitation facilities including assistance for planning, expansion, renovation and purchase of initial equipment, recodified the nation's oldest grant-in-aid program and placed emphasis on expanding services to the more severely handicapped and expanded the vendor program for the blind.

3. In 1975 the following public laws were enacted:

PL 94–103, The Developmental Disabilities Assistance and Bill of Rights Act.

PL 94–142 The Education of all Handicapped Children Act.

4. A vast uncodified body of state law exists usually targeted for the provision of services to specific groups of handicapped people.

B. *Scope of the Problem*

There are more than seven million children and at least 28 million adults in America with physical and mental handicaps.[4] Individuals with handicaps are all too often excluded from schools and educational programs, barred from employment or are underemployed because of archaic attitudes and laws, denied access to transportation, buildings, and housing because of architectural barriers and lack of planning, and are discriminated against by public laws which frequently exclude individuals with handicaps or fail to establish appropriate enforcement mechanisms. Not the least of the problems is the fact that the American people are simply unfamiliar with and insensitive to difficulties confronted by individuals with handicaps.[5]

Discussion of Problems

The development of new technology and the adaptation of existing technology for the handicapped have been hampered in the past in inattention to the definition of discrete, project oriented tasks,[6] by the lack of a suitable basic science to support the managerial decision processes required,[7] by a scarcity of people trained and educated in the application of engineering principles to the handicapped,[8] and by the high cost of technical failures induced by non-perception of real needs.[9] Several investigators have commented that the process of applying technology developed in other settings to the settings of health care includes not only the design of devices, but also the development of techniques for problem definition and the management of programs leading to solutions.[10]-[12]

Boundaries exist between society, the handicapped, technology and medicine. Failure to bring elements across these boundaries has led to many problems that negate successful technologic intervention in the field of handicapping conditions.

Despite the admonitions of Lewis Thomas,[13] most people still refer to all expenditures on health and the absence of health as the Health Industry. This unfortunate lumping has led to many problems. Some are conceptual: Health Care has become the new name for clinical medicine. Others are mechanistic: Health Care Delivery has become the new name for the processes by which clinical medicine is practiced. However, the "crisis in health" (that includes services to the handicapped) is neither conceptual nor mechanistic; it is financial. The Health Industry is a rapidly escalating contributor to the Gross National Product.[14] The Social Security Administration, which records the national health expenditure, reported that the nation's health bill increased from $12 billion in 1950 to $94 billion in fiscal 1973.[15],[16] During this period, the portion of the Gross National Product spent on health rose from 4.6% in 1950 to 7.7% in 1973 (see Figure 4).

As noted by Burger[17] one of the first issues raised for public examination because of the pressures of cost is the relation between investments made nationally for health and the resulting "purchased health." It has generally been assumed that the products of basic and applied research are translated into the technologies that eventually become the armamentarium of those engaged in the process of bringing about change.

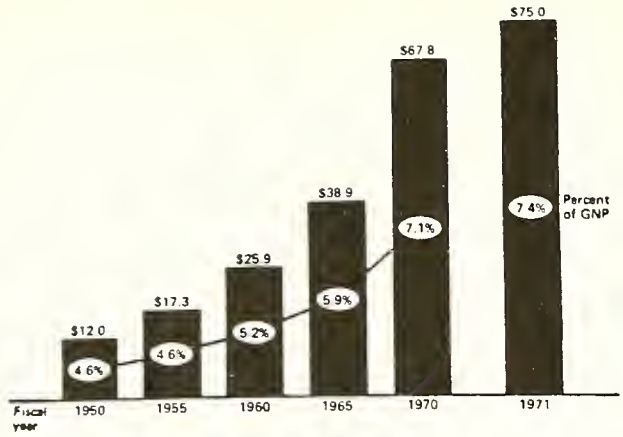


Figure 4. National Health Expenditures (per billion dollars) and Percent of Gross National Product (GNP) for Selected Fiscal Years from 1950 to 1971. Data from Rice and Cooper (15).

In the process of applying technology to the cure or containment of handicapping conditions and for the betterment of handicapped individuals, the hypothesis may not be a valid one. The problem may be that technology has only been applied partially to solutions for the handicapped. Much of the discussion about the utilization of technology for the solution of societal problems, exemplified by the problems of the handicapped, has been concerned with the needs of research, with the relative weight given "basic research" as compared with "applied research" and not with the administrative techniques used to conduct and manage that utilization. As pointed out by Gershinowitz,[18] ". . . very little is said about the processes involved in the application of research, about the mechanisms by which successful research could be used for the solution of major social problems.[11] The usual sequence of basic research, applied research, development, and use of research products seems an obvious logical and chronological order, especially to research workers. However, in those areas in which the application of research has been most successfully accomplished, the reverse order has been prevalent. Thus, if one's primary concern is with the use of knowledge to produce change, then the order should be: 1) The use of existing knowledge to produce the desired change (i.e., to allow individuals with handicaps to live their lives independently, with dignity, and with integration into community life); 2) When existing knowledge is incomplete or insufficient, applied research to find the missing knowledge; 3) In those areas in which lack of fundamental understanding limits the scope of applied research, basic research for understanding the nature of the needs; 4) And for those areas without even an understanding of the nature of the needs, basic research without regard to any possible area of application.

In the latter sequence the most essential element in the application of the fruits of research, especially costly research, is a mechanism for transforming knowledge into the action that produces change. To be specific, in the area of technology applied to the problems of the handicapped, the most essential element is a mechanism for the transfer of Technology.

State of the Art

Technology, even technology applied to the needs of the handicapped, is too broad to be detailed here. Moreover, no one can predict what environmental change, what genetic mutation or what new infective agent might drastically alter the needs of the handicapped or lead to new handicapping conditions. What can be accomplished is a generic division and subdivision of technology into its component parts, the drawing of conceptual frameworks of reference for the description of health services delivery and for the services needed by the handicapped. And finally a strategy for technologic assessment is necessary to answer the questions, "Where are we (with technologic applications)?" "How do we know when we are there?" and "Where do we go from here"?

A. *Technology—Its Generic Divisions*

Technology is synonymous neither with instrumentation nor technique though it encompasses both. The applications of technology may well take the form of an instrument or a technique, but should not be confused with them. Technology is a process. In the area of aids to the handicapped, gadgets and gimmicks have too often been substituted for technology.

In the view of Thomas[13,19] there are three levels of technology that ought to be distinguished. The first is termed "*nontechnology*", impossible to measure in terms of its capacity to alter either the natural course of handicapping conditions or their outcome. It is what is meant by the phrases "caring for" and "standing by." It is indispensible. It is valued highly by the providers of services for the handicapped as well as the handicapped themselves. It is sometimes called "supportive therapy."

It is what physicians used to be engaged in at the bedside of individuals with diphtheria, meningitis, poliomyelitis, lobar pneumonia and other infectious diseases that have now come under control.

It is what professionals must do now for patients with intractable cancer, severe arthritic disabilities, multiple sclerosis, cerebral vascular accidents, and various mental and developmental disorders.

At the next level up is a kind of technology termed "*halfway technology*" by Thomas.[19] This represents the kinds of things that must be done after the fact of disability in efforts to compensate for the incapacitating effects of certain disorders whose course one is unable to do very much about most likely because of our state of ignorance regarding the fundamental disabling processes.

This level of technology is, by its nature, at the same time highly sophisticated and profoundly primitive. The outstanding examples in recent years are the transplantations of hearts, kidneys, and other organs and the equally spectacular fabrication of artificial organs and limbs. It is the wonderfully technical world of sensors and transducers that stimulate or simulate the body functions. It is the kind of technology that in the public mind and in the media is viewed as a breakthrough rather than as a stopgap.

This is the kind of technology, technique or instrumentation that one must use until there is a genuine understanding of the basic mechanisms involved in disease. It is characteristic of this kind of technology that it costs an enormous amount of money and requires a continuing expansion of facilities. It requires an increasing pool of specialized personnel to operate it. The only thing that can move technology away from this level is new information.

The third type of technology is the kind that is so effective that it is taken for granted and attracts little public notice. This is the genuinely *decisive technology* of modern science. This is the really high technology of medicine based on the result of a basic understanding of disease mechanisms. When it becomes available, it is relatively inexpensive and relatively easy to deliver. Most important as regards a review of applied technology to the institution of the full rights of citizenship to the handicapped is the realization that this type of technology, the *decisive technology,* need not necessarily be medical at all. The striking and consistent declines in death rates from some infectious diseases (e.g., tuberculosis and streptococcal diseases) known to cause disabling conditions, could not be attributed to specific therapeutic interventions since the causative organisms in each case were not recognized until well after the trends were established (see Figures 5 and 6). In these cases, environmental factors were thought to have played an important role. With respect to technologic intervention in other disabling disorders, especially genetic disorders, the likelihood of true breakthroughs of *decisive technology* is thought to be high.

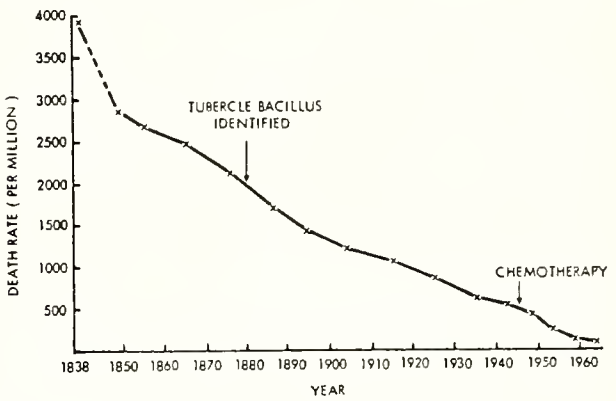


Figure 5. Mean annual death rate from pulmonary tuberculosis in England and Wales from 1838 to 1962. From McKeown and Lowe (20). Cited in Ref. 17.

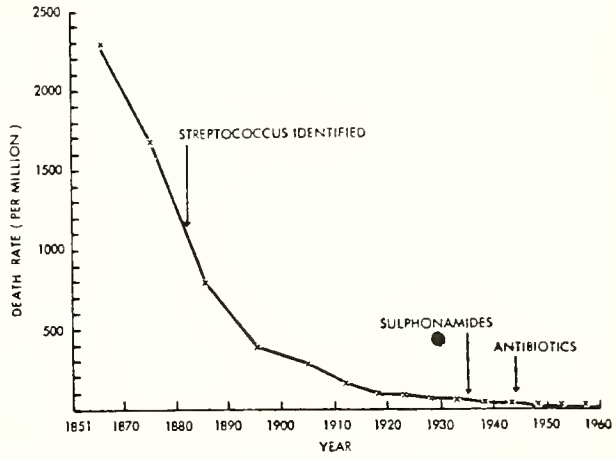


Figure 6. Mean annual death rate in children less than 15 years old from scarlet fever in England and Wales from 1870 to 1960. McKeown and Lowe (20). Cited in Ref. 17.

B. *Health Services Delivery—A Conceptual Framework*

Many conceptual frameworks for the description of health services delivery in this country

have been proposed and discussed.[21 23] Common to all is the realization that managerial and operational frameworks for the delivery system must be developed to allocate resources rationally to the overall delivery of services to the handicapped and to measure the impact of services offered. This theoretical description must have counterparts in actuality so that the impact of developed and implemented technology can be measured. Accordingly, the conceptualized system must be characterized according to its inputs, medium to be transformed and its outputs. One conceptual system is shown in Figure 7.

C. *Needs of the Handicapped*

If the goal of full citizenship for handicapped individuals is to be achieved, service delivery systems must be structured according to a conceptual framework not unlike stepping stones[24] (see Figure 8).

D. *Strategy for Technology Assessment—The Missing Element*

For each of the services or needs listed in the conceptual frameworks, evaluation is required. Since each effort is different and at a different level of sophistication, only a general evaluation scheme will be described.

The system of delivering health care service may be viewed as the employment of inputs, such as doctors, nurses, outpatient clinics, hospitals, population nutritional levels, environmental quality, and other factors, producing an output—the "level of health" or "level of habilitation."

There is much controversy in the economic and public health literature about the proper measure of "level of health."[25 26] Some of the commonly used definitions of this measure are the percentage of people sick at any time, the average number of days lost to illness, the expected earnings stream of the population suitably defined. Regardless of the measure of output, one might imagine a "community health" function that expresses the "level of health" output in terms of the levels of inputs, such as number of doctors, number of hospitals, etc. Such a function is referred to by the economists as a production function and by the engineer as a transfer function. We shall employ the former term.

Intuitively, we should expect our "community health" production function to have several obvious properties:

- An increase in the level of any input should produce an increase in the level of output. If we increase the number of diagnostic services in a community, we expect community health to increase, measured by any available standard.
- Subsequent increases in the level of any one input, all other inputs being held at a constant level, should produce ever smaller absolute increases in the level of output. The reasons is that inputs may complement one another. For example, the marginal benefit from adding additional kinds of occupational therapy service, while holding the number of occupational therapists constant, and thus, in effect, spreading them thinner—will decrease for each service added.
- The marginal increase in output resulting from an increase in any one input will be greater if other inputs are also increased. This also results from the complementary property; i.e., increases in the number of services will have a greater effect if the number of doctors, or more appropriately, other personnel, is increased at the same time.
- Many different combinations of inputs can produce the same level of output. In some

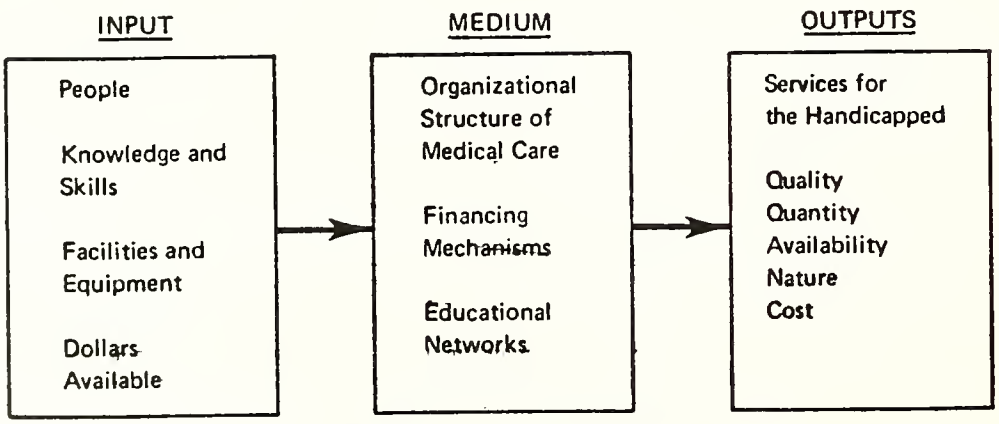
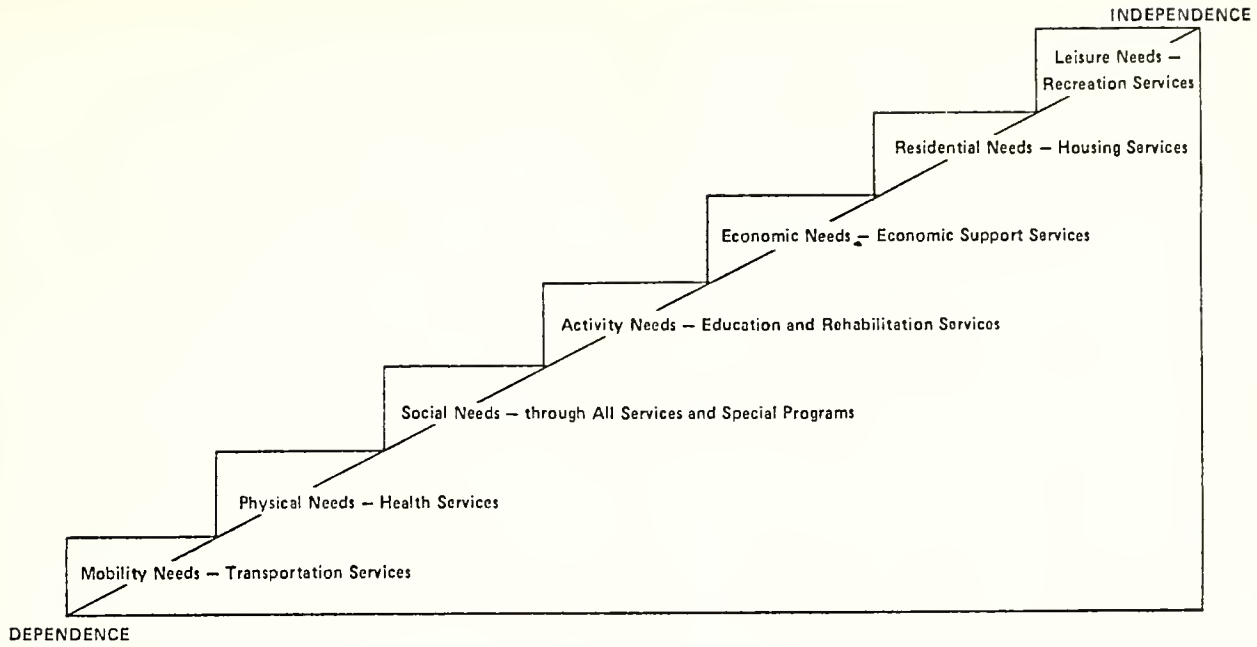


Figure 7. Health Services Delivery—Conceptual Framework



Source: Adapted from M. Santamour and K. Rose, "Defining the Problem of Mental Retardation: A Functional Model" (Paper presented at Region X AAMD Meeting, 1969.)

If the goal of full citizenship for handicapped individuals is to be achieved, service delivery systems must be structured as stepping stones to facilitate as much as possible the movement from dependence to independence.

Figure 8. Needs and Services for the Handicapped–A Conceptual Framework

sense, inputs to community health substitute for each other; that is, a given level of health might be produced by alternative combinations of nurses and doctors, therapists and clinics, etc.

The production function concepts offer three major advantages in an economic analysis of technologic intervention.

- Determination of the substitution and complementary properties of the inputs to a production process; production functions enabled one, in the context of community health care, to determine how the various inputs substitute for each other (nurses for doctors, paramedical people for nurses, and so on) and complement one another (doctors working in hospitals, nurses working for doctors, etc.) in the production of any level of output.
- Determination of the optimum combination of categories of input resources under a given constraint; when combined with a budget constraint, the production function permits determination of the input resource mix that yields the greatest output for a given cost constraint, or, alternatively, the lower cost at which a given output can be achieved.
- Determination of the returns to scale, or the multiplicative effect on output measure caused by proportionate changes in the level of inputs.

There have been many examples of the successful application of production function models to problems in industry and government.[27,28] Without a clear picture of the generic types of technology available, the system and settings to which technology is to be applied and a scheme for assessment, the problems at the boundaries of technology and the needs of the handicapped will not be crossed.

EXAMPLES OF EXISTING TECHNOLOGY APPLIED TO SOME NEEDS OF THE HANDICAPPED

An Example of Thomas' "Nontechnology"

The private sector, represented by countless service organizations, voluntary health agencies and just plain people has achieved most success in the area of "nontechnology" technology. Sympathy, empathy and patience are not quantifiable outputs of any assessment program yet they are real.

In the area of Nontechnologies, empirical studies related to helping relationships or behavior change seem to bear out at least two general conclusions. First of all, when indices of congruents, positive regard, and empathy are combined as summary descriptions of clinician style, positive change occurs in the handicapped individual, positive change occurs when the index is high, and negative change occurs when it is low (Bergan, 1969). In other words, there is general agreement, even among many non-Rogerians, as to the benefit of the warm, understanding and integrated relationship, although some question exists as to whether these conditions alone are sufficient for behavior change. Of paramount importance, however, is that the quality of a helping relationship does have certain technical qualities that can be related to techniques within the "non-technical" area.

Secondly, there is adequate evidence to support some general conclusions about technology within the helping relationship in the behavioral therapy realm. There is little question that the behavioral therapies, or the conditioning and modeling of behavior therapies, are affective means of change (Patterson, 1966.) While these techniques have been available for some time, it is only now that they are beginning to be recognized and deliberately manipulated in a manner to produce empirical findings permitting the translation of techniques into usable technologies.*

Accidents are a prevalent cause of disabilities, especially in lower age groups. Some concept of their impact is seen in Figure 9. In nonfatal accidents, rehabilitation, job retraining and job placement are vital ingredients in the total mixture of services provided. Such services are rendered by dedicated people, most effectively in service organizations as part of a system that includes medical care, often monetary assistance and specific research. As a group, the insurance industry and specific disease foundations have been able to mount the kind of broadly based centers that include the "nontechnologic" technologies.

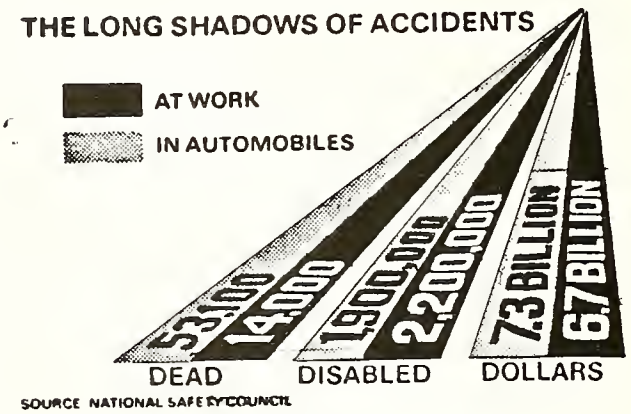


Figure 9

The public sector, except for Federal institutions, is in general, too removed from the direct provision of services to individuals. By the direct monetary support of private sector groups that are more directly involved with rendering service, and by placing a high priority on the support of *people* in people mediated technology, the public sector can continue to contribute significantly to this kind of technology. Specifically, the public sector can return to a level of stability in their dollar support that can enable providers in the private sector to attract and retain people and programs that are directed toward the "caring for" and "supportive therapy" that characterize the "nontechnologies."

One aspect of an existing type of this technology can be reviewed to exemplify an earlier comment on obstacles to utilization, namely ". . . technology has only been applied partially to solutions. . . ." (see Discussion of Problems page).

A report to Congress, authorized by the Rehabilitation Act of 1973* and entitled "The Role of Sheltered Workships in the Rehabilitation of the Severely Handicapped" stated that only about one in ten handicapped persons finds work

---

* I am indebted to J. D. Parham, Ph.D. of the Research and Training Center in Mental Retardation at Texas Tech University for the suggestion to include the material on behavioral change therapy.

*Prepared by Greenleight Associates, Inc. and reported by UPI in the *Washington Star*, January 5, 1976.

after being trained in special workshops. Apparently, the assumption behind the rehabilitation effort was that most handicapped persons are placeable in jobs and that all that was needed to accomplish their placement was vocational rehabilitation. In fact, however, the ability to obtain a job is not merely dependent on a person's job skills. It is also dependent on the community. Even sanctions, subsidies or quotas for hiring handicapped persons were not seen as being successful in altering the statistics on employment of the handicapped.

As an example of well intentioned but perhaps misdirected effort, the Sheltered Workshop Program calls attention to the need for comprehensive planning and broad input from a variety of disciplines before a categorical (i.e., vocational rehabilitation) program is instituted. The example further highlights the need for cooperation between the public and private sectors in the initial analysis and planning processes that antedate program implementation. Failure to effect this type of early cooperation has led to the failure of more than one technologic intervention, not limited to the application of technology to the needs of the handicapped.[10 29]

Examples of Thomas' "Halfway Technology"

The most active and best known examples of technologic intervention are in the group of applications that compensate for the effects of disorders that lead to handicapping conditions. The list of machines, instruments, devices and gadgets is endless. Almost all sciences at the boundary between technology and medicine have representative efforts in meeting some need of the handicapped. All efforts in this category are repairative, substitutive or compensatory for some function lost. The lost functions run a wide gamut. Figure 8 lists the general functional needs of the handicapped. Most handicapped persons regardless of the type of handicap, have a need in several if not all of the functional categories cited. Thus, it is not surprising, therefore, that a purely technologic fulfillment of one area of need will not have great impact on the total needs of the handicapped.

Sensory aids to the blind is a field that can be used as an illustrative case study. During the past 35 years, many efforts have been made to develop useful electronic aids for the blind. These are primarily devices that aid mobility or access to printed matter. The field has been summarized by Nye and Bliss.[30] But no matter which of the thirty or so electronic aids that enhance the mobility of the blind works best in a specific situation, none will significantly answer the needs of the blind if building codes do not safeguard his access, if recreation facilities are not available, or if ignorance and prejudice block acceptance in jobs for which that person is now available.

A recent promising advance in the area of access to printed matter[31] may run into similar problems. The developers* of a computerized device that scans printed pages and reads them aloud in a voice that gives appropriate stresses and pauses, have taken extraordinary pains to involve more than engineering specialities in the analysis of need and the various stages of development yet the cost of the unit may be prohibitive. These simple examples of technology in just one area, electronic aids to the blind, are representative of the still unmet needs of the handicapped. There are multiple similar examples that could be cited: Electromechanical aids for orthopedic disabilities[32] and architectural barriers that impede access by the handicapped.[33]

It seems that the private sector has access to the expertise of multiple technologies. Especially, private foundations are best able to assemble a variety of experts from both sectors, public and private. But overall direction seems placed best in the public sector, provided consistent, stable planning and follow through can be guaranteed.[29]

Example of Thomas' "Decisive Technology"

The most effective technologic interventions for the handicapped go almost unnoticed. They are taken for granted. Most efforts in this category are preventive: Vaccines for immunization against contracting the diseases that lead to handicapping conditions or avoidance of some environmental or pharmacologic toxin that affects fetal or immediate perinatal well-being.

The most spectacular recent example was the development of the polio vaccine. It is important to note that the final realization of that success was based on a long history of seemingly unrelated scientific discoveries in techniques of cell culture and viral immunology that enabled Sabin and Salk to complete the attack on the once dreaded disease, poliomyelitis.

Another illustrative example, currently under debate, involves the policy for Rubella vaccina-

*Kurzweil Computer Products, Cambridge, Mass.

tion. Congenital Rubella "German Measles" lead to cataracts, deafness, congenital heart disease and mental retardation. The spectrum of utilization of services and dollar costs of the Congenital Rubella Syndrome are seen in Figure 10.

Since 1969, when rubella vaccine was first licensed, the policy for vaccination has been a matter of controversy. Debate continues, but it is evident that disciplines other than pure technology are required. A recent report by a group of investigators at Harvard,[34] supports with data, a change in current U.S. rubella vaccination policy. For the purposes of reviewing technologic interventions the sequence of events cited in their report well illustrates how the pure science community must interact with both the public and private sectors to effect complete or nearly complete, removal of rubella from the list of causes of handicapping disorders. Even compliance with vaccination policies required a coordinated massive educational program of professional and lay persons alike. Obstacles to the implementation of such policies after the scientific (i.e., technologic) portions of the program have been completed, stem primarily from the lack of data usually derived from broadly based population studies and the techniques of mass media advertising and education. Such are not matters for technologists alone.

Promising Technology

Technologic applications on the horizon will undoubtedly impact directly on handicapped individuals in diagnostic and therapeutic modalities and indirectly on the "non-medical" needs of the handicapped (e.g., recreation, mobility and education.).

The field of electronic circuity has been revolutionized by micro miniaturization techniques primarily developed by the space industry. Alternative power sources to replace standard batteries, some using new nuclear energies, are already in use. Thus, any prosthetic device that now employs signal pickup sensors, and battery power can be reduced in size and weight, last longer and work more efficiently. Sophisticated microcircuits have already reduced computer processor size to a degree where intricate mobility prosthetics can be entirely programmed.

Laser technology is another example of technology developed elsewhere, being used to aid the handicapped. A special laser beam walking cane* has been used as a mobility aid for the blind. It probes ahead for the blind person, detecting dropoffs, straight-ahead obstacles and obstacles appearing between chest and head height warning the traveler with auditory and tactile signals.

*Bionic Instruments, Inc., Bala Cynwyd, Pennsylvania 19004

SPECIAL SERVICES	UTILIZATION (%)	DURATION & COST
Newborn nursery—excess care	20.0	5 days' intensive care + an extra 5 days = $1,350/hospitalization
Schooling for moderately deaf	23.5	$8,000/yr × 10 yr
Schooling for totally deaf	24.5	$8,000/yr × 20 yr
Heart surgery	35.0	$5,000/operation
Cataract surgery	20.0	$1,000/operation × 2 eyes, 15% failure resulting in blindness
Schooling for blind	1.4	$7,500/yr × 20 yr + $1,500/yr × 40 yr for special equipment
Schooling for moderately retarded	8.4	$3,500/yr × 15 yr
Schooling/institutionalization for severely retarded	30.0	$7,800/yr × 40 yr

Figure 10. Estimated Frequency of Utilization of Special Services by Persons with Congential Rubella Syndrome and Estimated Duration and Cost of These Services.[34]

A similar technique, called electroretinography (ERG) is a means of measuring the electrical response of the retina to a flash of light. In effect ERG measures retinal function. A most promising application has been the early diagnosis of a group of hereditary diseases characterized by degeneration of the retina, the film-like "seeing-back" layer of the eye.

People with handicaps due to loss of neurosensory control (e.g., muscular paralysis, loss of bladder and bowel control) are being aided by implanted microcircuits and minute energy sources. Another technical solution to similar control problems is offered by "biofeedback" techniques whereby the handicapped are retrained to control body functions by a kind of "reconditioning" of their reflexes.

Non-medical technologies will undoubtedly contribute to the overall well being and education of the handicapped. Cable TV, an as yet under utilized medium for specialized mass communication, is one such example. Even satellite communication offers unlimited potential for recreational and educational needs of the handicapped. A collaboration between the governments of Canada and the United States will result in the launching of a Communications Technology Satellite (CTS). It will be available to each country for a variety of communications experiments. The satellite will permit bidirectional audiovisual connections between ground terminals.

THE FUTURE

No one can foretell with certainty the next technologic breakthrough or the next environmental or mutational alteration that will present us with new solutions or new problems for the handicapped. To be sure, educational and communication technology seem poised at the brink of innovations that could significantly satisfy some needs of the handicapped. Techniques for prenatal diagnosis of genetic and biochemical disorders that can lead to handicapping conditions seem promising. But unless there is adapted a technology for analysis, development and application of solutions to practical needs, the impact of future discoveries or mutations will be unrealized.

CONCLUSIONS AND RECOMMENDATIONS

From the foregoing review of (1) definition and statement of needs of the handicapped, (2) definition and subdivision of technology, (3) the setting of generic frameworks of reference for applied technology and the needs of the handicapped, a delivery system that encompasses a broad view of technologic interventions for the handicapped, and a plan for assessment of intervention, and (4) the study of selected examples of technology, it is evident that the requirements for successful technologic intervention are:

A. More efficient organization at a national level

B. Planning based on better demographic and sociologic data

C. Specialized manpower of the type now being termed "clinical engineers"[8 35 36] who can join the team of specialists working for and with the handicapped.

D. Coordinated and stable funding of technologic research, intervention and assessment based on national rather than parochial objectives.

It should also be evident that neither the private nor the public sectors alone can marshal the spectrum of effort required for the successful intervention of technology for the handicapped. Each has areas of wherewithal to contribute.

The public sector seems better able to develop a national sense of mission, set national priorities, establish consistent funding policies based on those priorities and marshal the necessary specialists of diverse backgrounds including scientists, sociologists and educators. The National Academy of Sciences, through committees and assemblies within the National Research Council, is a particularly striking example of this type of role for the public sector.

The private sector seems better able to provide specialized expertise, conduct basic research, field test and produce techniques and instruments and educate specially targeted consumers of technologic interventions through a multiplicity of societies and foundations.

Together, both sectors share dual responsibilities for the collection and dissemination of information that sensitizes the population, handicapped and non-handicapped alike, to the problems and needs of the handicapped. Coordinated and consistent overtures to funders, both federal and private must be made. And finally,

the process of implementation requires combined effort of providers and consumers, public and private.

BIBLIOGRAPHY

1. Wolf, J.M. and Anderson, R.M. The Multiply Handicapped Child. Springfield, Ill. Charles C. Thomas, 1969 pp. 363–67.
2. Adapted from "New Deal for Handicapped in Jobs, Housing, Recreation . . ." U.S. News and World Report. July 22, 1974, p. 39.
3. Galbraith, J. K. The New Industrial State. Houghton Mifflen Co., Boston, Mass., 1967, p. 12.
4. Ford, G. Statement by the President. Fact Sheet, White House Conference on Handicapped Individuals, Nov. 22, 1975.
5. Report of the Committee on Labor and Public Welfare. Rehabilitation Act Amendments of 1974. Ninety-third Congress, 2nd Session. Report 93–1139, 1973, p.32.
6. Johns, R.J. Is Biomedical Engineering Fulfilling Its Destiny? Ninth IBM Medical Symposium, Burlington, Vt., October 24–26, 1968, p. 13.
7. Garrett, C.W. and Von Renner, L.C. Experience and Perceptions of Aerospace Technology Transfer to Health Care Delivery. Presented at the Tenth Goddard Memorial Symposium, Washington, D.C., March 13–14, 1972.
8. Staros, A. The Clinical Engineer. Presented at the Annual Winter Meeting, American Society of Mechanical Engineers, Detroit, Mich., Nov. 11–15, 1973.
9. Hollingsworth, G.L. The Puzzle of Social Sector Markets: How to Swallow a 500-Ton Marshmallow. Innovations. No. 30, p. 22, 1972.
10. Rutstein, D.D. and Eden, M. Engineering and Living Systems: Interfaces and Opportunities. The MIT Press, Cambridge, Mass., 1970, pp. 303 ff.
11. Reynolds, O.E. In "Utilization of Space Biosciences Technology" Vol. 1, The Transfer of Technology. The Interdisciplinary Communications Associates, Inc., Washington, D.C., 1971, p. 135.
12. Ayers, W.R., Murray, D.E., Aller, J.C. et al. Mobilizing the Emergency Room Record. A Case Study in the Capture of Technology Developed Elsewhere for Use in Health Care Delivery. Computers in Biology and Med. 3:153, 1973.
13. Thomas, Lewis. Aspects of Biomedical Science Policy. An address to the Institute of Medicine, Fall Meeting, Nov. 9, 1972, Washington, D.C.
14. Basic Facts on the Health Industry. Report of the Committee on Ways and Means, 92nd Congress, First Session. U.S. Govt. Printing Off., 1971, Washington, D.C., pp. 8–9.
15. Rice, D.P. and Cooper, B.S. National Health Expenditures, 1929–1971. Social Security Bulletin, Social Security Administration, Washington, D.C., U.S. Dept. HEW, Jan., 1972.
16. Social Security Administration. National Health Expenditures, Fiscal Year 1973. Research and Statistics Note No. 24–1973. Washington, D.C., U.S. Dept. HEW, Dec. 27, 1973.
17. Burger, Edward J. Health and Health Services in the United States. Ann. Int. Med. 80:645, 1974.
18. Gershinowitz, Harold. Applied Research for the Public Good—A Suggestion. Science. 176:380, 1972.
19. Thomas, Lewis. The Technology of Medicine. New England J. of Med. 285:1366, 1971.
20. McKeown, T., Lowe, C.R. An Introduction to Social Medicine. Oxford Blackwell Scientific Publications, Ltd., 1966.
21. Flagle, C.D. Communications and Control in Comprehensive Patient Care and Health Planning, Ann. N.Y.. Acad. Sci. 161:714, 1969.
22. Kissick, W.L. Health Policy Directions for the 1970's. New Engl. J. Med. 282:1343, 1970.
23. Garfield, S.R. The Delivery of Medical Care. Sci. Am. 222:15, 1970
24. Adapted from: Santamour, M. and Ross, K. Defining the Problem of Mental Retardation: A Functional Model. Presented at Region X AAMD Meeting, 1969.
25. Donabedian, A. Evaluating the Quality of Medical Care. Health Services Research. Ed. by Donald Mainland, Milbank Memorial Fund, 1967, pp. 116–203.
26. Packer, A.H. Applying Cost-Effectiveness Concepts to the Community Health System, Operations Res. 14:227, 1967.
27. Walters, A.A. Production and Cost Func-

tions. An Econometric Survey. Econometrics 31:1–66. 1963.
28. The Theory and Empirical Analysis of Production. Brown, M. Ed. for Columbia Univ. Press, N.Y., 1967.
29. Medical Engineering Development and the Role of the Federal Government. A Study Performed for the Director, NIH. Aerospace Corporation, July 5, 1967.
30. Nye, P.W. and Bliss, J.C. Sensory Aids for the Blind: A Challenging Problem with Lessons for the Future. Proc. IEEE 58:1878, 1970.
31. Machine Reads to the Blind. Focus on the News. Medical World News 17:6, 1976.
32. Staros, A., Peizer, E. and Rubin, G. Application of Electromechanical Technology to Orthopedic Disabilities. Presented to IEEE International Convention and Exposition, March 26–30, 1973.
33. Arts and the Handicapped: An Issue of Access. A publication of the Educational Facilities Laboratories, 850 Third Ave., N.Y., N.Y. 1975.
34. Schoenbaum, S.C., Hyde, J.N., Bartoshesky, L. et al. Benefit-Cost Analysis of Rubella Vaccination Policy New Engl. J. Med. 294:306, 1976.
35. Oakes, J.B. Clinical Engineering—The Problems and the Promise. Science 190:239, 1975.
36. Aller, J.C. The Coming Generation of People to Match the New Technology. Presented at Joint Measurement Conference, National Bureau of Standards, Nov. 12–14, 1974.

ATTACHMENT

HANDICAPPING CONDITIONS BY DIAGNOSTIC CATEGORIES

- Developmental Disabilities
- Mental Retardation
- Epilepsy
- Cerebral Palsy
- Autism
- Learning Disabilities
- Emotional Disturbance
- Other Physically Handicapping Conditions (Excluding above mentioned developmental disabilities)
- Major Communications Disorders
  - Speech
  - Vision
  - Hearing
  - Combined Deafness/Blindness

I. Neurologic:
- A. Syndromes of cerebral dysfunction:
  1. Cerebral palsy
  2. Mental deficiency
  3. Epilepsy
  4. Hyperkinetic–behavior syndrome
- B. Sensory disorders:
  1. Vision–blindness, partial sight
  2. Hearing–deafness, other hearing defects
  3. Speech–articulatory disorders
     a. Stuttering
     b. Cleft palate
     c. Aphasia
  4. Perception–conceptual and reading disorders
  5. Kinesthetic–tactile disorders
- C. Miscellaneous:
  1. Hydrocephaly
  2. Brain-tumor effects
  3. Progressive cerebral and lenticular degeneration
  4. Cerebromacular degenerative diseases
  5. Other progressive neurologic diseases

II. Orthopedic:
- A. Residuals of trauma and accidents:
  1. Sequelae of burns
  2. Spinal-cord injuries
  3. Amputations
- B. Malformations:
  1. Achondroplasia and chrondro-dysplasia
  2. Foot deformities, dislocation of the hip
  3. Spina bifida and related congenital defects
  4. Cleidocranial dysostosis

III. Residuals of Infection:
1. Poliomyelitis
2. Osteomyelitis
3. Periostitis
4. Arthritis
5. Tuberculosis
6. Rubella

IV. Myopathies and astrophies:
1. Muscular dystrophy
2. Myotonia
3. Amyotonia congenita
4. Myasthenia gravis

- A. Miscellaneous:
  1. Osteogenesis imperfecta and related disorders
  2. Bone tumors

V. Cardiac:
1. Congenital heart disease
2. Acquired heart disease

VI. Respitatory:
1. Asthma
2. Cystic fibrosis
3. Tuberculosis
4. Bronchiectasis

VII. Genitourinary:
1. Congenital renal anomalies
2. Nephrosis
3. Chronic glomerulonephritis

VIII. Endocrine–Metabolic
1. Pituitary disorders
2. Thyroid disorders
3. Parathyroid disorders
4. Adrenal disorders
5. Diabetes
6. Lipoid disorders

IX. Blood:
1. Leukemia
2. Hemophilia

X. Psychiatric:
1. Psychoses
2. Neuroses and anxiety states
3. Psychosomatic disorders

XI. Other
1. Cytogenetic defects
2. Amino acidopathy

Source: Adapted from E. Denhoff and I. Robinault, *Cerebral Palsy and Related Disorders* (New York: McGraw-Hill Book Company, 1960).

Dysentery	Pneumonia
Tuberculosis, all forms	Bronchitis, emphysema, and asthma
Meningococcal infections	Other diseases of the respiratory system
Acute infectious encephalitis	Peptic ulcer
Infectious hepatitis	Appendicitis
Typhus and other rickettsioses	Intestinal obstruction and hernia
Venereal disease	Gastritis, duodenitis, enteritis, and colitis
All other diseases classified as infective and parasitic	Cirrhosis of liver
Malignant neoplasm, including neoplasms of lymphatic and haematopoietic tissues	Nephritis and nephrosis
	Hyperplasia of prostate
Benign neoplasms and neoplasms of unspecified nature	Complications of pregnancy, childbirth, and the puerperium
Diabetes mellitus	
Avitaminoses and other nutritional deficiencies	Congenital anomalies
Anemias	Birth injuries, difficult labor, and other anoxic and hypoxic conditions
Nonmeningococcal meningitis	
Active rheumatic fever	Other causes of neonatal mortality
Chronic rheumatic heart disease	Symptoms and ill-defined conditions
Hypertensive disease	All other diseases
Ischaemic heart disease	Motor vehicle accidents
Other forms of heart disease	All other accidents
Cerebrovascular disease	Suicides
General arteriosclerosis	Homicides
Other diseases of arteries, arterioles, and capillaries	Legal intervention
Influenza	All other external injuries

[1]*Stedman's Medical Dictionary*, 22nd Ed. (Baltimore: William and Wilkins Co., 1972).

PART B
TECHNOLOGY:PAST AND PRESENT

Wars have always made the public aware of the physically handicapped. Since the end of the Civil War, the Federal government has provided limbs for its amputee veterans. In 1917, the Association of Limb Manufacturers of America was founded when the Surgeon General of the Army called limbmakers to Washington to consider the problems of the World War I amputees. Until the end of World War II, the technology applied to handicapping conditions was almost entirely related to prosthetics. Attention to other areas of technology and to concerted consumer advocacy is a relatively recent phenomenon. By 1954, the Department of Health, Education and Welfare's Office of Vocational Rehabilitation (OVR) supported research and training in orthotics and sensory aids as well as prosthetics; such OVR efforts were coordinated with those of the Veterans Administration, the Department of Defense, and other Federal Departments and HEW agencies.

Today, technology related to medicine, equipment, and treatment concepts is making some positive contributions to the prevention and amelioration of disabling conditions. The poliomyelitis vaccine has reduced occurrences of paralysis. The rubella vaccine prevents many prenatal defects. Seat belts prevent whiplash and other injuries. Hearing and sensory aids, heart pacemakers, artificial limbs and electrostimulation are used to ameliorate the handicaps caused by irreversible physical diseases and injuries.

For technology to assist the handicapped, the concepts and techniques of the physical sciences and engineering must be applied to the traditional biomedical outlook of persons engaged in the rehabilitation effort. This has led to the development of the discipline of "bioengineering" which, in the parlance of those concerned with the handicapped, is also referred to as "clinical engineering" or "rehabilitation engineering". Whatever the term, these technological processes are concerned with increasing the capabilities of individuals who are functionally impaired by (1) restructuring their environments and (2) providing them with orthotics, prosthetics, or other required aids to assist them in adjusting to their environments. The goals of this assistance are to make individuals capable of undertaking activities by themselves and, thereby, to increase independence.

The development of new devices and techniques or the adaptation of existing ones to aid the handicapped has been difficult for several reasons: a lack of application-oriented tasks as well as the required basic science to support decision-making by policy makers, a scarcity of trained rehabilitation or clinical engineers who know the problems and needs of the handicapped, and the high cost of marketing devices or aids that have a limited number of potential customers. These give rise to several questions:

1. Are the objectives of technology for the handicapped geared to meet the needs of the handicapped? Have sufficient studies been made to determine the benefits of technological advances?
2. Can the technological progress be transferred? Are the requirements of the technology to aid the handicapped within the existing state of the art or is a further technological breakthrough required?
3. What is the time frame in which new aids and techniques can be achieved?
4. What are the cost-benefits involved? Can the handicapped afford the new technology? If they can't, what kind of funding will be required?
5. Are there commercial organizations which are willing to manufacture aids of quality and provide the necessary training and services for potential users? Will subsidy be required for the training and services?

TECHNOLOGY: AN OVERVIEW

A response to some of the questions posed is contained in the report, "Science and Technology in the Service of the Physically Handicapped," published in 1976 by the Committee on National Needs for the Rehabilitation of the Physically Handicapped, National Research Council, National Academy of Sciences (NAS). The NAS Report, as it shall be referred to hereafter, has this to say:

> "If devices are ever to transcend being laboratory curiosities, they must be developed, evaluated, and produced in adequate quantities and . . . made available to potential "consumers". Traditional market mechanisms do not appear to be entirely adequate for this transition . . . . Even when federal or private funding sources support product development, choosing a potential product to underwrite is

difficult. Development and market introduction costs range from ten to one hundred times the research feasibility investment. Since only a small proportion of research projects lead to marketable products, the cost ratio of development to research is very high. Developmental efforts cannot compete in total cost with the many diversified research proposals. Support of research is easier, safer, and cheaper . . . . The route from early feasibility studies into widescale deployment is often blocked by the frequently insuperable obstacles represented by product and market development . . . . A possible resolution to these difficulties might be the formation of a private-public corporation charged with the development and market introduction of really promising rehabilitation engineering products. The central problem is the lack of venture capital. A combination of government, industry, and organizational funding could provide adequate resources to start the process with the most promising candidates. Choosing particular products is difficult, but a separate corporation with its own organization free of direct influence from the network of federal and private agencies that support and do research, would ensure objective choices . . . . The manufacture, distribution, and sale of successful products must be assumed by private enterprise. Exclusive licensing arrangements could prove an incentive to industry to assume products. Pay-back royalties or provisions from sales could, over time, renew the venture capital resources of the proposed developmental corporation."

Areas of Concern

For technological advances to become actualities in aids and services for handicapped individuals, there are five major areas which require attention:*

1. Coordination among researchers, product developers, service providers, and consumers; as well as among the Federal agencies that fund technology-related programs for the handicapped;
2. Cost analyses for both the allocation of research and development resources, and long-range cost effectiveness of the development of technological aids;
3. Marketing efforts to reduce product costs and to reach the concerned handicapped population;
4. Training to permit handicapped individuals to make use of technological advances; and
5. Adaptation of the teaching of technology to serve many needs rather than that required by a single device or concept.

Sweden's Model

As a government model for developing aids for the handicapped, Sweden's deserves attention.

"First, the Swedish Board for Technical Development finances on a pay back basis industrial research and development for products that have commercial potential, especially if they are unique and have export prospects. Second, under the National Health Program, all aids and prosthetic devices, evaluated and approved by the Institute for the Handicapped, are provided free to the user, thus guaranteeing a market to the manufacturer. Third, in order to finance the pilot production needed for initial evaluation, one percent of the total national budget for the purchase of devices is available to manufacturers on a competitive basis, with allocation decisions made by the Institute for the Handicapped and by the Ministry of Health. In FY 1975–1976, the total Swedish government cost for all services to the handicapped population of over one million persons* was $1.2 billion or 1.8% of the gross national product. Of this, $68 million was used to purchase free aids for the handicapped, $1.4 million for government funding of research and development for the handicapped, and $0.23 million on government support for the introduction of developed aids.

A somewhat comparable incentive could be created in the United States if, when national health insurance is legislated, provision is made for approving and providing appropriate rehabilitative devices as part of health care. This could extend the current provisions of the Veterans Administration to the general population."**

*Mueller, Max W., "Research Needs Related to Science and Technology for the Handicapped" in "Science, Technology and the Handicapped", American Association for the Advancement of Science Report No. 76–11, August 1976.

*In the same year the population of Sweden was 8 million and the total government budget was $23 billion. Data from Birger Roos, Technical Director, Swedish Handikappinstitutet, August 24, 1976

**NAS Report

SOME MAJOR HANDICAPPING CONDITIONS, SOME TECHNOLOGICAL ADVANCES, AND FURTHER REQUIREMENTS

All of the quotes in the following discussion related to specific handicapping conditions are from the NAS report.

Visual Impairment

Practical substitutes for the blind or visually impaired are primarily aimed at providing (1) access to printed material and (2) "unhampered mobility in a normal environment." Other applications range from sign reading to gesture observation, from graphic and pictorial instruction to scenic and artistic enjoyment.

As for other handicapping conditions, the statistics on the blind and visually handicapped are generally poor. The number of legally blind in the United States varies from 300,000 to 450,000, while a 1965 National Health Survey estimates that 1,700,000 persons were functionally blind. A large portion of these persons earn limited incomes or are unable to work at all. The development and distribution of sensory aids could transform these persons into full-fledged wage earners and taxpayers "who may amply return the government's investment in rehabilitation."

Nonvisual reading aids of various kinds are already available, and others are on the drawing boards. There are relatively inexpensive speech synthesis devices such as "talking pocket calculators." More elaborate and costly advances use computer pattern-recognition techniques in conjunction with speech synthesis to permit the direct translation of printed English into audible speech for the blind user. The economics of such elaborate systems are still prohibitive, but the technological breakthrough has been made.

The many mobility aids presently available must be used with the long cane, although it appears that some of this could be developed as supplements to the long cane or guide dog in limited situations. During the last ten years, there have been several attempts to develop a prosthesis for the totally blind by direct coupling to the nervous system. "These experiments are hazardous, difficult, and expensive. At present it is difficult to forecast the effectiveness of this approach as a rehabilitation technique."

"With few exceptions, the devices needed by the visually impaired (as opposed to the totally blind) are simple, inexpensive, off-the-shelf items that industry knows how to make. What is needed now, even more than new technology, is wider availability of the benefits to be derived from current technology."

Hearing and Speech Impairment

In 1970, communicative disorders were estimated to cost $500,000,000 in direct expenditures in addition to a loss in earning power of about $1,750,000,000. About 13 million persons have hearing impairment; another four to five million brain disorders impairing communication and voice disorders. Hearing aids have been available for some time, and some speech devices along with specialized training have also been in use.

Telephones with volume control can be used by the deaf, as can telecommunications systems that enable deaf persons to type through telephone lines. The latter enables direct communication between two persons who are equipped with the required teletypewriters. Unfortunately, many businesses and industrial organizations are unaware that such visual equipment is available for deaf people to communicate with others who are deaf or those who can hear. There is then a need to educate the public about the availability of such equipment, as well as to develop better methods to train the deaf in its use. Additional research is needed to develop low cost, easy to use visual equipment for the deaf.

More recently, aids for the deaf that analyze speech have been considered; although they have not thus far proved effective, indications are that further research will make such devices useful.

> "Possibilities exist for aids that apply electrical signals to the auditory nervous system via implanted electrodes. To date, it has not been possible to demonstrate gains in speech reception superior to those expected from the use of a simple vibrator. The implant approach has inherent risks and is costly because of the necessary surgery and medical care . . . ." (Because of difficulties such as these, the implant approach requires much more research effort.)
>
> "The devices available for production of voice in patients whose larynx has been removed are primitive. Quality is poor, power low, and pitch control is absent. The fact that such relatively primitive devices can be used by patients to

produce understandable speech implies that there is a great deal of room for progress. With current technology, pocket-sized speech synthesizers are possible, and devices such as these may fill the need of a person made mute by disease or trauma."

Manipulation and Locomotion

Deformities and amputations, paralysis, and skeletal joint destruction limit capacity for movement. The design evaluation and use of prosthesis and other aids to movement call for a multidisciplinary effort by surgeon, bioengineer, prosthetics technician, and physical therapist; and "the integration of diverse training backgrounds, vocabularies, and problem-solving strategies requires the explicit organization of project or institute structures."

Orthoses are used to help correct contractures and to compensate for instability and misalignment of intact limbs by providing static support. Technological advances have resulted in the use of plastic materials, mostly vaccuum-formed polypropylene, which have increased the mechanical effectiveness, comfort, and appearance of orthoses.

Multichannel surface stimulation to provide simultaneous hip, knee, and ankle control is in the experimental stage; and developments are needed to coordinate stimulus timing with individual gait pattern. Spinal-cord injured patients have been walking between parallel bars with the aid of an experimental electronically controlled and articulated bilateral limb orthoses. Problems with this system include precarious balance because there is no sensory input. Also, the system is not portable because it requires a tremendous amount of energy to operate.

"Muscle fatigue under electrical stimulation is a real problem, but current research indicates that desirable biological changes in muscle to increase its fatigue resistance can be achieved by systematic training regimes. An attractive alternative being studied is ". . . direct multichannel afferent stimulation" to the spinal cord to activate motor nerves.

Orthopedic management of arthritic deterioration of joints, was revolutionized by the introduction of total hip-joint replacement. Artificial joints, either commercial products or experimental models, are now available for most body joints; but clinical success has been greatest in the hip for which the ball and socket joint has been accurately reproduced by mass production techniques. Other joints have more complex anatomy and do not lend themselves to mass production. Problems related to all joints replacements include surgical infections, secure fixation, accurate contouring of the joint, and provision of normal anatomical functioning. Orthoses are also being used to relieve joint pain. Thus, existing technology permits individuals with deformities, paralyses, or joint destruction to adjust to their work and personal environments

"To improve devices necessary for motion in and manipulation of the environment, priority should be given to research and development of methods for control of prostheses and orthoses, methods to improve sensory feedback, hardware improvement, methods to attach devices to the operator, and cosmetic covers. The psychosocial acceptability of new or improved devices must be taken into account. . . . Aside from the very significant psychological aspects of overcoming a handicap (e.g., depression, lack of motivation), the ultimate conquest of paraplegia, quadriplegia, and disabling brain injuries awaits discoveries that will allow regeneration of the damaged nerve fibers in the spinal cord and brain. Since regeneration can occur in the peripheral nervous system, it seems entirely possible that recovery following transection of long tracts in the spinal cord may also become a reality someday . . . . Basic neurobiological research is currently being carried out on regeneration of the central nervous system. Studies on nerve tissue culture provide information on the requirements for growth and duplication of nerve cells. Such work may ultimately provide keys to understanding why neurons die and fail to regenerate following injury in adult human subjects."

REHABILITATION ENGINEERING CENTERS

In September 1970, the groundwork was laid for the establishment of Rehabilitation Engineering Centers (RECs) to improve the quality of life of the physically handicapped through an interdisciplinary approach that combined the efforts of medicine, engineering, and related sciences. Representatives of Federal agencies and professionals in rehabilitation research, education, and patient

services formulated the following objectives for the centers:

1. To engage in research and development;
2. To collaborate with laboratories and industry to carry new devices through research, development, clinical evaluation, production and patient use;
3. To exchange research and other information with other Centers and institutions on a continuous basis;
4. To cooperate with other Centers in the clinical evaluation of technological developments;
5. To make new devices and techniques available to patients; and
6. To educate physicians, engineers, and other professionals about these new devices and techniques, emphasizing the need to make them available to patients throughout the nation.

As of January 1977, there were eight established RECs, each specializing in a core area of rehabilitation. Two others, scheduled to be operational in 1977, will specialize in Functional Electrical Stimulation of the Upper Extremities and Automotive Design for the Disabled. The eight operational RECs and their Core areas are:

Location	*Core Area*
1. Downey, California	Functional Electrical Stimulation of Paralyzed Nerves and Muscles
2. San Francisco, California	Sensory Aids
3. Chicago, Illinois	Internal Total Joint Replacement
4. Wichita, Kansas	Vocational Aspects of Rehabilitation
5. Boston, Massachusetts	Sensory Feedback Mechanisms
6. Philadelphia, Pennsylvania	Neuromuscular Control Systems
7. Houston, Texas	Effects of Pressure on Tissue
8. Charlottesville, Virginia	Spinal Cord Injury

The first two RECs were funded on February 1, 1972. All of them were established in institutions which had already demonstrated ability in rehabilitation engineering, were associated with a university with medicine and engineering departments, and provided continuing rehabilitative services to patients in a clinical environment. The Rehabilitation Act of 1973 specifically mandates that 25 percent of all R&D appropriations to the Rehabilitation Services Administration (RSA) must go to support the RECs. REC funding by RSA for fiscal year 1977 is $7,250,000. RECs also receive funds from other Federal agencies and States for specific research, demonstration and training.

A Biomedical Engineering Program (BEC) has been established at the National Institutes of Health (NIH); close coordination among the REC and BEC programs and other activities of RSA and NIH avoids duplication of efforts and facilitates an exchange of information and developments. Cooperative arrangements also exist between Rehabilitation Services Administration and BEH and the Departments of Defense, Housing and Urban Development, and Transportation; the National Aeronautics and Space Administration, the National Science Foundation, and the Veterans Administration.

Once a Rehabilitation Engineering Center develops a new device and demonstrates its effectiveness on its own patients, other RECs will be asked to confirm this effectiveness. Production of the device must follow if it is to serve a significant number of patients. The Centers must, as noted above, "collaborate with laboratories and industry to carry new devices and techniques . . . to active production and patient use." But the limited market for many devices and the difficulty of getting third parties, such as Blue Cross-Blue Shield and Medicare, to pay for new devices often makes it difficult to arrange for production

A few Centers have been successful by involving industry early in the development of a device. In some instances, when a market for a device has not been established, a government agency has guaranteed the purchase of a specified quantity of the device.

PRODUCING THE OPTACON

While there has been an increase in sensory aid technology in the past decade, there has never been a determination of the requirements of the labor market related to sensory aids. One example of what can be done in this area has been the development of the Optacon.

A device about the size of a cigarette pack that a blind person can hold in one hand, the Optacon enables such a person to "see" so that he can write with the other hand—for instance, to fill out an application form or to write a check. Such a device could not be produced ten years ago because knowledge about circuitry had not been developed. By 1971, when a prototype of the Optacon was built, it could be mass produced.

With the aid of a grant from the Mellon Foundation, the Optacon Fund was established to combine the expertise of the clinical engineer with the skills of the rehabilitation specialist to expand employment opportunities for the blind. The Optacon Fund and the California Department of Rehabilitation's Employment Development Program for the Blind established a program to develop new entry-level employment opportunities for the blind by using sensory aids and adaptive devices. Sensory aids for specific jobs were to be recommended; when there was a need for a device that didn't exist, rehabilitation engineering was to be used to develop the new aid. In addition, information about existing sensory aids applicable for employment of the blind was catalogued and disseminated.

In the first year of its operation, this program placed 24 totally blind or legally blind persons on jobs that they would have been unable to hold without the appropriate sensory aids. In some jobs, the instruments used by sighted workers were modified. Among the blind who were employed were an electronics technician, a U. S. Geological Survey employee who monitors earthquake activity, a refrigeration mechanic, a librarian, and a radio newscaster. All work with sensory aids. All appear to be successfully accomplishing the tasks of their new found jobs.

RSA: WORKSHOPS AND TECHNOLOGY PRIORITIES

The Rehabilitation Services Administration (RSA) is specifically charged with establishing the expertise and technological competence necessary to stimulate the development of methods for applying advanced technology. RSA recently sponsored a number of workshops to define priority areas for further research and development. Some of these workshops dealt with functional electrical stimulation, driving aids and special vehicles for the disabled, and mobility for spinal-cord impaired people. Others dealt with upper and lower extremity prosthetics and orthotics, internal prosthetic devices, pressure effects on soft tissue, environmental barriers, sensory aids and locomotion, and analysis of gait. In addition, RSA has developed a research and evaluation strategy in consultation with the Rehabilitation Engineering Centers. The results of such workshops are a major factor in determining priorities for new technology.

BEH CONFERENCES

Recently, the Bureau of Education for the Handicapped (BEH) sponsored five major conferences to determine the research required to provide better education to the handicapped. From these conferences and other input to BEH,* five major issues emerged that relate to science, technology and the handicapped, namely the need for:

(1) better science education for the handicapped;

(2) more occupational opportunities in science and technology, and occupational training of the handicapped in a broad range of fields;

(3) more coordination, research and development of technological aids to help deliver educational services to the handicapped;

(4) use of technology in the classroom; and

(5) application of technology that will ameliorate disabilities so that handicaps will not develop.

In the application of technology, BEH is particularly concerned with reading machines, hearing aids and mobility, communication and environmental control aids for those with orthopedic disabilities. For example, in addition to the Optacon, BEH finds promise in another visual-to-tactile aid, the Argonne Braille Translation and Storage Machine; in visual-to-auditory aids, such as the Kurzwell and Stereo-Toner; and visual-to-visual aids such as Randsight.

Since most visually impaired persons are not completely blind, other technology areas that require further work include closed-circuit TV, overhead projectors, lenses, and mobility devices. For the speech and hearing impaired, additional technology, as well as training, is required in the development and use of visual and tactile presentations, and in the use of residual auditory skills.

VA EFFORTS: A TOTAL CONCEPT

The Veterans Administration (VA) has been and is now one of the prime forces in the use of technology to benefit the handicapped. Immediately following World War II, the VA took the lead in improving the state of the art in prosthetics by funding educational programs to teach various professionals about the treatment

*Mueller, Op. cit.

and technological developments from research laboratories. In the 1960's the VA, along with HEW, expanded its efforts to include orthotics and, later, the application of technology other than that restricted to prosthetics and orthotics.

Today, the VA is actively engaged in rehabilitation engineering research: developing and supplying handicapped veterans with prosthetics and orthotics; neuromuscular, sensory and skeletal implants; and monitors of all kinds. And VA centers have made practical application of the resulting research.

One VA center is using technological aids and concepts to aid aged persons with handicapping conditions; the agency plans to expand this to its other facilities. A VA Prosthetics Center* presents another example of the ways in which technology is used at such centers: bioengineering developments, particularly rehabilitation engineering concepts, are used to provide direct care to amputees and to those with spinal cord or orthopedic disabilities; special emphasis is placed on the technology of adaptive equipment and special vehicles for the handicapped driver; bioengineering programs for the aged and spinal-cord injured patients are to be emphasized. In addition, attention will be given to standards, specifications and a compliance testing program for prosthetics, orthotics and technological aids as well as to the distribution of orthopedic shoes, spinal orthoses, sensory aids and hydraulic devices. Further, training programs are to be conducted on the use of prosthetics, orthotics and other aids.

NASA: AN EXAMPLE OF TECHNOLOGY TRANSFER

In its Biomedical Applications Division, the National Aeronautics and Space Administration (NASA) gives attention to the transfer of technology to problems of the handicapped and their rehabilitation, and to the interaction between Federal and other public agencies involved in helping the handicapped.

NASA has been involved in the development of a rechargeable cardiac pacemaker battery that "doesn't fail". A polyurethane silicone plastic foam, developed for passenger seats, has found a wide variety of medical applications, and a commercial company was formed to market the material. An automated mobile metabolic analyzer, developed for SKYlab, is being used to measure energy expended by orthotic-equipped patients. Other devices include a hand-finger flexor; a switch that operates controls by eye; and breath-actuated switches to operate television sets, book page turners and lights.

Joint technological efforts by NASA and the Atomic Energy Commission have resulted in the development of pure carbon, biologically compatible with human tissue, that is used in heart valves and with prosthetics. The attachment of the prosthesis is by a quick disconnect pin which NASA developed for umbilical connections in a space vehicle. The device is implanted under the skin into the bone; the skin grows around the carbon. The prosthesis is built around the pin; the amputee hits the prosthesis to hold it in place. Three patients are now using such a prosthesis; one has been in use for more than nine months.

Another device is used to move a paralyzed limb. A small receiver is embedded in the leg and a wire goes to a nerve near the knee; there is an antenna outside the skin that is connected to an electronic unit worn in the belt. A switch in the heel transmits a signal to the belt unit each time a step is taken.

TECHNOLOGY TRANSFER AND PRODUCTION

The capability and resources exist to develop technology for the handicapped that will make them increasingly productive members of society. Further, existing technology can be exploited to provide results in the immediate future. Technology related to equipment and moving vehicles, instruments, computers and communications, which might be transferred to devices to aid the handicapped, has been developed at universities and other research facilities, by industrial organizations, and in governmental programs such as those sponsored by NASA and the Department of Defense.

In September 1976 hearings before the House Committee on Science and Technology, NASA's Assistant Administrator for Industry Affairs and Technology Utilization pointed out that there is sufficient existing technology to handle many of the problems facing the handicapped; new space-age technology is not what is needed. But questions remain:

*District 4, Region 1, Department of Medicine and Surgery, VA, January 27, 1975

. . . Who is going to pay for the transfer of the existing technology into marketable devices for the handicapped?

. . . Who will mass produce the devices? Can industry be convinced to make the investment? Private foundations? Or must government take the initiative?

For handicapped people to enjoy optimum utilization of technological advances, there must be a concerted effort involving Federal, State, and local agencies; private industry; and consumer advocacy, private foundations and other nonprofit organizations.

The Federal Government must continue to fund research and training and to provide matching grants to states to purchase rehabilitation aids. Internal research at NIH and the VA must continue, and further efforts must be made to coordinate the activities of the various Federal agencies.

Information on technological advances and existing aids and techniques must be made readily available, and the Federal government should foster the development of a comprehensive catalog that includes information related to all handicaps.

State and local agencies must expand programs that provide aids and training to the handicapped; training for the clinical rehabilitation engineers, medical personnel and others involved in handicapped programs; and training for the handicapped themselves.

The role of private industry is difficult to assign, because many of the new aids, with high development costs, have a limited market. An economic model could be developed to show how the private sector can join forces with government agencies to provide more timely and better use of technology to aid the handicapped. The implementation of such a model may require direct government subsidy, tax rebates, or other economic incentives to encourage development when production is not profitable.

Some aids, of course, have utility for other than the handicapped and can be manufactured for the general public. The Handivoice System is such an aid; it can be used by banks to communicate with their customers. Voltras, the company that developed the system, has made an adaption useable by the speech impaired.

Private foundations and organizations can continue to provide services and aids directly to the handicapped; to educate the general public, professionals and paraprofessionals, and the handicapped; and to provide funding to produce aids when industry cannot. For example, production of the Optacon was made possible by a $1.5 million grant from the Andrew W. Mellon Foundation and government funds. Organizations such as United Cerebral Palsy and the Easter Seal Society have started their own or other vocational rehabilitation or research foundations.

CONCLUSIONS

1. For the major areas of disability, a comprehensive national study is required to determine not only the demography and technological needs of the handicapped, but also the costs and the proposed funding mechanisms for meeting these needs.

2. Industry must be given incentives so that it will assume an active role in getting technological aids to the handicapped.

3. Technology developed by NASA and other Federal agencies should be transferred to other government agencies or industrial establishments where it can be used to develop aids for the handicapped. There must be a concerted effort to use the results of research.

4. A national technical journal could be established to disseminate information on technological aids and devices that aid the handicapped. This journal would include information from any source. It could be part of an existing information facility or a new resource that specifically responds to the information needs of handicapped. It must be able to provide up-to-date information quickly. Some of the information required is already being collected by a number of facilities, and a concerted effort should be made to use what mechanisms already exist and to avoid duplication.

5. While training requirements related to the services and needs of the handicapped transcend all professional and lay groups, there is a special need to train clinical rehabilitation engineers who can use related technological advances to solve specific problems of the handicapped and their vocational and social adjustment. The expansion of this new engineering discipline is vital if technology and rehabilitation are to maintain a close relationship.

SELECTED REFERENCES*

1. Aerospace corporation, "Medical Engineering Development and the Role of the Federal Government," Study for the Director, National Institutes of Health, DHEW July 5, 1967.
2. Aller, J.C., "The Coming Generation of People to Match the New Technology," Presented at Joint Measurement Conference, National Bureau of Standards, Gaithersburg, MD Nov. 12–14, 1974.
3. Ayers, W.R., Murray, D.E., Aller, J.C. et al., "Mobilizing the Emergency Room Record. A Case Study in the Capture of Technology Developed Elsewhere for Use in Health Care Delivery," Computers in Biology and Medicine, 3:153, 1973.
4. Brown, M., Ed. "The Theory and Empirical Analysis of Production," Columbia Univ. Press, N.Y. 1967.
5. Burger, Edward J., "Health and Health Services in the United States," Ann. Int. Med. 80:645, 1974.
6. Donabedian, A., "Evaluating the Quality of Medical Care," Health Services Research, edited by Donald Mainland, Milbank Memorial Fund, 1967.
7. Educational Facilities Laboratory, "Arts and the Handicapped": An Issue of Access, 850 Third Ave., NY, NY, 1975.
8. Flagle, C.D., "Communications and Control in Comprehensive Patient Care and Health Planning," Ann. N.Y.. Acad. Sci. 161:714, 1969.
9. Ford, Gerald, Statement by the President, "Fact Sheet, White House Conference on Handicapped Individuals," Nov. 22, 1975.
10. Garfield, S.R., "The Delivery of Medical Care," Sci. Am. 222:15, 1970.
11. Garrett, C.W. and Von Renner, L.C., "Experience and perceptions of Aerospace Technology Transfer to Health Care Delivery," presented at the Tenth Goddard Memorial Symposium, Washington, D.C., March 13–14, 1972.
12. Gershinowitz, Harold, "Applied Research for the Public Good—A Suggestion," Science. 176:380, 1972.
13. Hollingsworth, G.L., "The Puzzle of Social Sector Markets: How to Swallow a 500-Ton Marshmallow," Innovations, No. 30, 1972.
14. Johns, R.J., "Is Biomedical Engineering Fulfilling Its Destiny?" Ninth IBM Medical Symposium, Burlington, Vt., Oct. 24–26, 1968.
15. Kissick, W.L. "Health Policy Directions for the 1970's." New Engl. J. Med. 282:1343, 1970.
16. McKeown, T. and Lowe, C.R., "An Introduction to Social Medicine," Oxford Blackwell Scientific Publications, Ltd., 1966.
17. Medical World News, "Machine Reads to the Blind; Focus on the News," 17:6, 1976.
18. Nye, P.W. and Bliss, J.C., "Sensory Aids for the Blind: A Challenging Problem with Lessons for the Future," Proc. IEEE 58:1878, 1970.
19. Oakes, J.B., "Clinical Engineering—The Problems and the Promise," Science 190:239, 1975.
20. Packer, A.H., "Applying Cost-Effectiveness Concepts to the Community Health System," Operations Res. 14:227, 1967.
21. Reynolds, O.E. in "Utilization of Space Biosciences Technology" Vol. 1, The Transfer of Technology. Interdisciplinary Communications Associates, Inc., Washington, D.C., 1971.
22. Rice, D.P. and Cooper, B.S., "National Health Expenditures, 1929–1971," Social Security Bulletin, Social Security Administration, DHEW, Washington, D.C., Jan., 1972.
23. Rutstein, D.D. and Eden, M., "Engineering and Living Systems: Interfaces and Opportunities." MIT Press, Cambridge, MA, 1970.
24. Santamour, M. and Ross, K., "Defining the Problem of Mental Retardation: A Functional Model," presented at Region X AAMD Meeting, 1969.
25. Schoenbaum, S.C., Hyde, J.N., Bartoshesky, L. et al, "Benefit-Cost Analysis of Rubella Vaccination Policy," New Engl. J. Med. 294:306, 1976.
26. "Social Security Administration, National Health Expenditures, " Fiscal Year 1973. Research and Statistics Note No. 24–1973., SSA, DHEW, Washington, D.C., Dec. 27, 1973.
27. Staros, A., "The Clinical Engineer," presented at the Annual Winter Meeting, American Society of Mechanical Engineers, Detroit, Mich., Nov. 11–15, 1973.
28. Staros, A., Peizer, E. and Rubin, G., "Application of Electromechanical Technology to Orthopedic Disabilities," presented at the

*This list was prepared by Ayers, William R., MD, Assistant Dean for Curriculum, Georgetown University, Washington, DC

International Convention and Exposition, IEEE March 26–30, 1973.
29. Thomas, "Aspects of Biomedical Science Policy," an address to the Institute of Medicine, Fall Meeting, Washington, D.C., Nov. 9, 1972.
30. Thomas, L., "The Technology of Medicine," New Engl. J. Med. 285:1366, 1971.
31. US Congress, 92nd, 1st Session "Basic Facts on the Health Industry." Report of the Committee on Ways and Means, U.S. Govt. Printing Off., Washington, D.C., 1971.
32. US Congress, 93rd, 2nd Session, "Rehabilitation Act Amendments of 1974, Report of the Committee on Labor and Public Welfare, 93–1139, 1972
33. US News and World Reports, "New Deal for Handicapped in Jobs, Housing, Recreation," July 22, 1974.
34. Wolf, J.M. and Anderson, R.M., "The Multiply Handicapped Child," Charles C. Thomas, 1969.
35. Walters, A.A., "Production and Cost Functions: An Econometric Survey," Econometrics 31:1–66. 1963.

EARLY DIAGNOSIS AND EARLY INTERVENTION IN HANDICAPPING CONDITIONS

Awareness Paper Prepared by

Dennis Whitehouse, M.D.
Director, Diagnostic and Evaluation Center
For Handicapped Children
The John F. Kennedy Institute
Baltimore, MD

TABLE OF CONTENTS

	Page
Preamble	49
Handicapping Conditions	49
Definition	49
Description	49
Early Recognition	49
Later Onset	50
Legal Aspects	51
Early Diagnosis	52
General	52
(1) Prenatal	52
(2) Perinatal	53
High-Risk Babies	53
(3) Postnatal (Infancy)	54
(4) Childhood	54
(5) Adolescence	55
(6) Adult Life	55
Early Intervention	55
(1) To Prevent Further Disability	56
(2) To Produce Improvement in the Handicapping Condition	56
(3) To Help the Established Disability	56
Professional Involvement	56
(1) The Physician	56
(2) The Nurse	57
(3) The Nurse Practitioner	57
(4) The Social Worker	57
(5) The Teacher	57
(6) The Vocational Rehabilitation Counseler	57
(7) The Specialized Professionals	58
(8) The Parents	58
Service Providers	58
Voluntary Organizations	58
Data Collection	58
Summary	59

PREAMBLE

The term "handicap" derives, in modern times, from sporting circles, as a concept of carrying an extra burden so as to even up the relative abilities of two or more competitors. The better competitor is therefore given the greater handicap. Unfortunately, in the field of medicine, the handicap works in the opposite direction by tending to produce unevenness, both in competition and many other aspects of human interaction. This unevenness also produces awareness of differences between the handicapped and other persons. In turn, these differences may easily feed into attitudes of non-acceptance of those who are different, which is unfortunately an inherent trait of mankind. The handicapping condition may therefore create not only problems in functioning in a competitive world, but also may induce negative attitudes in that very section of the world where competition is more difficult.

These problems, however, are not basically inherent to handicapping conditions. Although handicapping conditions in most cases, by definition, are relatively static medical processes, there is often an evolution of events prior to these problems arising. Handicapping conditions range from those whose seeds are sown in early life and which slowly develop through school years to adulthood, to the later onset of a medical condition which may remit or arrest, leaving residual disability. Therefore, both the practical problem of handicapping conditions, and attitudes towards them, take time to evolve. Furthermore, there are many medical therapies which can be useful, both curatively and preventively during this period of time.

The importance of this time-base to a handicapping condition is that the earlier the intervention in these different processes, the more impact there is on preventing untoward consequences. Early intervention is therefore prophylactic as well as therapeutic. Early intervention must also imply early recognition as a prerequisite, and this in turn demands early and adequate diagnostic processes and treatment plans.

HANDICAPPING CONDITIONS

Definition

A handicapping condition is one where a medical condition exists which is liable to persist over a long period of time and which impairs the normal functions of the individual to a significant degree.

Description

Handicapping conditions include those which produce sensory impairment, such as blindness and deafness. They include motor disabilities of the nervous system or other disorders of locomotion, such as cerebral palsy, spinal disorders, loss of limbs, and other crippling conditions. They also include impairment of ability to learn, ranging from mental retardation to specific learning disabilities, as well as certain related organic behavioral syndromes. Epilepsy is a handicapping condition, although in many epileptics the major disability may be only society's attitude toward the afflicted individuals.

In addition to those of the central nervous system and locomotive system, handicapping conditions include a number of more general disorders such as chronic conditions of the cardiovascular, respiratory and other systems. These disabilities may impair function by slowing down the pace of or unmobilizing individuals. Chronic heart disease, hypertension, emphysema, or asthma are examples of this.

Because of these widely differing conditions, it is clear that the term, "handicapped", covers a wide range of disabilities and means that many general statements may not in fact apply to all situations.

Much individualization is necessary, and inevitably there is risk of conflicting needs. This paper must, out of necessity, generalize to a great degree, but the differences between handicapping conditions must be borne in mind.

Although the statistics of handicapping conditions are not totally relevant to the concept of early intervention and will probably be represented by other papers, it is perhaps important to look at some of the dimensions of the numerical frequency of different handicapping conditions, if only to emphasize how valuable early intervention can be. Table 1 lists the approximate numbers of school children with varyious handicapping conditions according to a U. S. Public Health Service report in 1971. The first three categories of eye care, hearing impairment and speech impairment clearly have implications for early intervention and represent a total of over 16 million children. Other disorders listed can also be helped and would also benefit from early intervention.

TABLE 1

Number of Handicapped School Children by Category (Source: DHEW, Public Health Service Publication 7137, 1971)

HANDICAP	*NUMBER*
Visually impaired	12,500,000
Speech impaired	3,200,000
Mentally retarded	2,700,000
Orthopedic problems	2,400,000
Hearing impaired	2,300,000
Cerebral Palsy	490,000
Seizures	450,000
Total	24,040,000

Table 2 lists the number of handicapped school children in 1969, according to the U. S. Office of Education. Although there appears to be a gross discrepancy in numbers, it must be remembered that there are differences in methods of identification and classification by severity. An incidence of 1% for learning disabilities is the lowest figure ever quoted. Even on the lowest estimates, it is clear that there are many millions of children with handicapping conditions, and these figures do not account for the adult population which is over twice as large. Therefore, handicapping conditions represent a considerable amount of human suffering and a loss of human resources.

TABLE 2

Number of Handicapped Children and Prevalence Rate in 5 to 19 Year Age Group (Source: US Office of Education, 1969)

HANDICAP	*NUMBER*
Speech impaired	2,112,600 (3.50%)
Mentally retarded	1,388,300 (2.30%)
Emotionally disabled	1,207,300 (2.00%)
Learning disabled	603,600 (1.00%)
Hearing impaired	347,100 (0.60%)
Crippled	301,800 (0.50%)
Visually impaired	60,400 (0.10%)
Multiply handicapped	35,000 (0.06%)
Total	6,056,100

Early Recognition

The two steps towards early intervention are early recognition followed by early diagnosis. Although diagnosis implies a large degree of

professional expertise, early recognition does not depend entirely on professionals.

The basis of early recognition is awareness of the unevenness, or differences in function, of an individual compared with the "norms" for that age and that social group.

For this reason, the first recognition of a handicapping condition may come from a parent, close relative or other lay person. This is essentially true of handicapping conditions evolving through childhood, although not so true of conditions which result from medical diseases that occur later in life. Nevertheless, a mother may first recognize differences in her baby, and parents are clearly in the "front line" for early recognition. This should be recognized as such and supported.

The two prime needs for parents are education and the availability of a professional with whom to consult.

Education of future parents should, in fact, begin in high school where both preventative and therapeutic intervention can be taught. Education in high school can also provide expectations for a girl as a future mother and a boy as a future father.

The next stage in education clearly lies with the expectant mother who can be provided with useful information prior to the infant's arrival. Again, such intervention can be preventative, as in the recognition of any departure from normal expectations either during the pregnancy or afterwards.

After the arrival of the infant, education of the parents continues, both within and outside the family. The concept of the extended family, with grandparents or other relatives, is vital to ongoing prevention, recognition and therapy. One of our major current social problems is the increased mobility of the family, which leaves grandparents behind and works against this concept. Many handicapping conditions have been recognized first by an experienced grandmother.

Outside the family group, the next most important aid to educating parents and to early recognition is the well baby care facility, whether provided as a public or private facility. Here, professionals such as doctors and nurses can utilize their own observations and those of the parents to recognize developmental or other handicapping problems. These facilities exist in both the private doctor's office and in the public health Well Baby Clinic.

Routine physical examinations in private or public, well-baby clinic screening situations rarely elicit much significant handicapping pathology, *but* routine questioning of parents and a select group of screening procedures, such as hearing and vision screening, may yield more valuable information.

Through childhood, once again, parents are often the first to recognize handicapping conditions and to seek professional help. At all ages, the parents' education must continue. Public information efforts, such as radio and television commercials which draw attention to language development, may facilitate parents' observations.

Outside the family group a wide range of professional services may augment any parental limitations in observation. Such facilities range from the indispensable public health nurses to social workers, teachers, and physicians. Although health professional groups are taught the principles of handicapping conditions, non-medical professions such as teaching and social service may not have this background. The question arises as to how the latter can best be informed about important aspects of early recognition of handicapping conditions.

Figure 1 indicates the comprehensive screening procedure used by a rural county to identify potential handicapping conditions of childhood and early adulthood. Unfortunately, only a small percentage of children are followed through a public program such as this one. Children from poor and culturally deprived families may not come to clinics to participate in such programs. Also, children seen by their private physicians are left out of such a public-sponsored program.

Even if all children could be recruited for such a screening program, there would not be sufficient professional staff to do the screening and provide the services that would be required. Lack of funds has curtailed public health nursing staffs in many jurisdictions. Since public health nurses or other trained practitioners are needed to implement a screening program for identifying handicapping conditions, new sources of financial support must be found if such programs are to operate effectively.

Later-Onset

Although recognition in childhood is true "early recognition," not all handicapping conditions exist at this age. Those conditions that exist at an early age are likely to be less obvious, more

difficult to recognize and therefore more easily missed. Later onsetting handicapping conditions are more likely to result from medical conditions which are more overt and therefore more easily recognized.

There are exceptions. One might cite hypertension as a producer of later handicapping conditions. A condition such as this requires specific screening programs, which in the case of hypertension must be lifelong. The program used in the health department (Appendix B) only takes this screening up to the age of 20 years. There are clear needs for screening for hypertension beyond this age; the risks are increasing and the needs are greater beyond 20 years.

The type of screening procedure used by a professional or group of professionals will differ according to the specialization of the professional and the nature of the clinic. No one professional can necessarily screen for all potential handicaps, and a multidisciplinary approach is needed. This approach is so closely linked with diagnostic procedures that it will be considered under the section on Early Diagnosis.

Early recognition represents an identification or screening process and must be followed by accurate diagnostic procedures.

Legal Aspects

Many of these screening programs are being mandated by various state and federal laws.

Public Law 94–142 establishes procedures for identifying and planning for the educational needs of handicapped individuals from at least the age of 5 to 20 years. This law is an amendment to PL 93–380, which in turn is an amendment to PL 91–230, the law which created the Bureau of Education for the Handicapped.

This law does not carry provisions for all handicapped individuals or for all handicapping conditions.

This law is also different from the laws of many states. Allowance is made in the Federal legislation whereby the age range can be lowered to 3 years, if compatible with local state laws. State laws continue to differ significantly from other state laws and the Federal legislation.

All of these laws are complex and need interpretation. All are legislating for remedies which are themselves not new to the medical field. Optimal treatment has always been advocated along these very lines. The new laws are, therefore, to be regarded as somewhat of a civil rights procedure.

A further complication is funding. There have been examples of States which have mandated early identification programs with no funds being appropriated until much later. Public Law 94–142 allows for progressive but slow increase in funding to a maximum of 12% of the population at risk. This figure is far less than the number of handicapped individuals who need to be educated.

There is also a compliancy problem as it relates to families. Public agencies may provide early recognition programs from birth or later, but how can we ensure that all children will be screened? The state of Illinois passed a law mandating early recognition of developmental disabilities by the age of 3 years. A screening procedure called DIAL was devised, but the diagnosticians could not find 3-year-olds to screen unless they happened to be in a State program.

Nevertheless, some success has been achieved. Maryland provided, in House Bill 234, for the setting up of mandatory screening for learning problems in childhood. The Maryland State Department of Education designed an early identification protocol which was first applied in the fall of 1975 to all children when they enrolled for the first time, either in kindergarten or first grade. This procedure is capable of recognizing a wide range of handicapping conditions in the central nervous system ranging from cerebral palsy to mental retardation and including behavioral and learning disabilities. It is hoped that this device will prevent the occurrence of situations such as dyslexic children being labelled as retarded or being made to repeat grades, based upon their reading scores, and not being referred for diagnosis and help until they reach the high school level. Hopefully, such children will be identified earlier and helped earlier.

An even older Federal program mandating early recognition is that providing Early Periodic Screening, Diagnosis and Treatment for children from birth to 21 years who are served by Medicaid.

This program was initiated under the 1967 Amendments to the Social Security Act, but the quality of the implementation has been uneven. In some states it is working well, but in others its performance is marginal. This program is not designed specifically for the handicapped, but will overlap the provisions of Public Law 94–142.

EARLY DIAGNOSIS

General

As mentioned earlier, a thorough diagnosis must precede any early intervention. The word diagnosis means "knowing through" and, indeed, the use of a diagnostic label such as "cerebral palsy" or "paraplegia" is of little value to the individual and should only be used for statistical or administrative purposes. What diagnosis really implies is accurate measurement of both abilities and disabilities in the handicapped individual.

It implies a medical assessment of the underlying disease process, whether it be brain damage or asthma. Any residual activity of a disease process must be assessed and, if necessary, treated. More relevant to the White House Conference on Handicapped Individuals, however, early diagnosis implies accurate assessment of each individual function of the handicapped person in terms of assets and deficits. Each functioning system requires individual assessment along these lines and the assets and deficits should result in a diagnostic profile. The diagnostic label commonly in use groups a large number of different individuals under one heading and may conceal important differences, rather than provide an accurate assessment of needs.

Diagnostic labels imply more similarity between individuals in a category than in fact is present, and should be replaced by diagnostic profiles.

Such a diagnostic profile, if carried out on every handicapped person to the level of our present technological ability, would be incredibly exhausting to the individual, time consuming, expensive, and in fact wasteful as much of the data would be irrelevant or duplicative. Such evaluations must, therefore, be designed with the needs of each handicapped individual in mind.

Nevertheless, the handicapped person himself is an individual within a group, and the diagnostic procedures do not have to be totally individualized. Certain diagnostic procedures can be used within the different handicapping conditions as a general measurement of function. Such diagnostic procedures will differ according to the handicapping condition, the system being tested and, even more so, the age level of the individual concerned. Diagnostic procedures may, therefore, be discussed best as a function of the following age groups:

(1) Prenatal
(2) Perinatal
(3) Postnatal (Infancy)
(4) Childhood
(5) Adolescence
(6) Adulthood It is clear from the concept of establishing a profile of categorical abilities, that multiple systems are to be evaluated. Similarly, it is clear that many professionals will and should be involved.

The basic concept of a diagnostic profile should include a multisystem evaluation of the individual and a multidisciplinary approach.

The multidisciplinary approach involves two concepts. The obvious one is the need for a specialist to evaluate a particular system. An example of this is an audiologist to measure hearing. The other concept is that of overlap whereby, for example, a neurologist and a psychologist may both end up with similar data on the central nervous system, perhaps differing only in the degree of sensitivity. This overlap should not be regarded as necessarily wasteful because it may help to establish the validity of some of the less clear-cut observations and to confirm the accuracy of the assessment; and thereby may lead to better intervention procedures.

The best example of the value of the multidisciplinary approach lies in measuring the abilities and disabilities of handicapping conditions involving the central nervous system. Here behavior and learning disabilities interact and interfere with measurement. Here, the multidisciplinary approach is absolutely essential. Even in apparently simple sensory deficits such as deafness, the overt handicapping condition may conceal underlying problems such as those related to language. Again the multidisciplinary approach protects against such omissions. In other handicapping conditions, such as paraplegia, issues are clearer; and although multiple disciplines may be needed, such as neurology, orthopedics, physical therapy or occupational therapy, overlap is not quite as essential.

(1) Prenatal Diagnostic Procedures

Although a small number of handicapping conditions are associated with genetic defects, such as Down's syndrome, and are, therefore, present in the individual from conception; and although a large number are associated with intrauterine conditions, such as toxemia of pregnancy or maternal rubella, and, therefore, at least present at birth, facilities for diagnosing handi-

capping conditions during the intrauterine period are somewhat limited. The family genetic history may provide information as to increased risk for certain handicapping conditions and must remain an important part of the diagnosis. Such data, however, only provide statistical information as to risks, and cannot be used as a firm prediction of diagnosis for any individual. This information does at least provide data as to the type of handicapping condition which might be encountered.

Similarly, data from the actual pregnancy may suggest the possibility of certain processes occurring which may lead to a handicapping condition. Use of certain drugs in pregnancy, such as the classical example of thalidomide; the occurrence of certain diseases, such as diabetes during the pregnancy; and certain other significant insults to the expectant mother, such as excessive exposure to X-rays, all carry a range of risks to the unborn fetus. Nevertheless, this information is again only statistical and is of less value in diagnosing conditions in the individual. Such information is extremely valuable in terms of prevention.

Complications of the pregnancy itself, such as bleeding at various times or the development of varying degrees of toxemia, also have significant correlation with fetal insult and later handicapping conditions. Again, the risk is statistical and cannot be applied to the individual, except as a "high risk" factor. In a few situations direct diagnostic procedures can be carried out during pregnancy. Radiography of the fetus can show skeletal abnormalities. There must be sufficient data to indicate real need for such testing, as the risk of irradiation to the fetus must be balanced against the chance of the investigation's being useful.

More recently, direct examination of fetal cells obtained by a relatively simple aspiration of fluid from the amniotic cavity of the uterus can give direct diagnosis of a narrow range of genetic chromosomal and biochemical disorders and can provide a firm diagnosis in a few conditions, such as Down's syndrome, which is a chromosomal disorder, or as Tay-Sach's disease, which is a biochemical disorder.

Although these are definitive diagnostic procedures, at this moment in time their scope is somewhat narrow. As our technology advances, extension of these procedures may be anticipated. The ability to recognize many severe handicapping conditions before birth may lead to increasing possibilities of extremely early intervention, including abortion, which in turn will lead to problems involving ethical considerations.

(2) Perinatal Diagnostic Procedures

Direct examination of the mother and observation of the fetus, in intrauterine life, during labor, and immediately after birth, constitute observations made in the perinatal period. These observations can be made directly upon the functioning of the individual infant and are much more a direct measurement of predictable function or dysfunction in the newborn baby.

As many handicapping conditions are present before or by this time and are, therefore, present at the moment of these observations, they should be diagnosible at birth. These observations may reflect an abnormal infant showing distress from the stimulation from a normal delivery. Others show signs of distress from obstetrical difficulties and may indicate a need for immediate active intervention.

After delivery, direct observations can be made on the actual function of the infant nervous system. Abnormal reflex activity such as poor sucking, lack of muscle tone, cardiac malfunctioning, or respiratory malfunctioning may indicate existing damage to the baby. These functions may be usefully measured by the APGAR Score which rates the degree of vital activity at different times after birth.

Some handicapping conditions present at birth, such as deafness or blindness, cannot be accurately identified at this moment in time unless they are accompanied by defects which are visible during the routine physical examination of the newborn infant. They can be recognized later by functional measurements. There is, indeed, considerable limitation to the recognition of handicapping conditions in the newborn infant unless such visible defects are present. Hopefully, increasing interest and skills in the care of the newborn will help recognize more handicapping conditions at birth even when manifestations are not so obvious.

"High Risk" Babies. The use of pre-existing factors such as genetic disorders in the family, disease in the expectant mother, and the various pre- and perinatal processes in the uterine environment mentioned above led to the concept of the "High Risk" baby in whom the risk of a handicapping condition being present was high relative to other pregnancies. Unfortunately, the yield from this assessment was so low, with so

many normal infants being born after apparently abnormal conditions had occurred, that this concept has been largely abandoned. The future for recognition of "High Risk" infants may lie more in early observations of their functioning. Such observations are attempts to recognize the earlier signs of handicapping conditions before classical medical signs are present, and will be carried out during the postnatal period and onwards.

(3) Postnatal (Infancy) Diagnostic Procedures

During this period of life we are dealing with an immature and incomplete organism. For this reason, many of the handicapping conditions are themselves immature, incomplete and difficult to recognize. Such conditions may be far more readily recognized later in life, but then the chance to intervene early is lost.

Visual and hearing problems may be difficult to recognize in many cases because the newborn infant responds minimally to such stimuli. Nevertheless, it must be emphasized that one does not have to wait for long, and certainly one does not have to wait for "cooperation" before such abilities can be tested. Severe disabilities of this type can be recognized within the first months of life. Some milder handicaps may show little functional loss, and are much more difficult to diagnose. Nevertheless, reasonably accurate diagnosis by expert hands is likely to be much easier than by less skilled hands.

Motor handicapping conditions can also be observed and measured during these early months. Mental retardation is a little more difficult to recognize early because the infant's function is largely motor-governed which is the least informative of the developmental signs. Caution must always be used in making diagnoses at this early age because the immaturity of the nervous system is so marked that evidence of abnormality in one part of the immature system cannot be used readily as evidence for abnormality in other parts. In addition, one cannot accurately predict the future of an abnormal system when one is measuring only a small part of the total functioning system. Caution is, therefore, needed before arousing anxiety in parents.

A number of handicapping conditions will present as physical defects. Examples of these are the varieties of spina bifida, cleft lip and palate, congenital abnormality in the heart and other systems, and a number of known syndromes presenting characteristic facial and other cutaneous and musculoskeletal abnormalities. These conditions normally present as obvious medical disabilities and are usually treated as such.

A number of disabilities may be somewhat delayed in showing themselves. Cystic fibrosis may not show up until later intestinal or respiratory problems develop. Congenital kidney disability may only show impairment of function after infections develop. A number of rare disorders present at birth may not evidence themselves until later years.

(4) Childhood Diagnostic Procedures

During the preschool years, the handicapping conditions of a developmental type, which were not severe enough to present in the early months or years of life, may show themselves by the occurrence of deviant developmental patterns. The child with deviant or delayed motor function, such as difficulty or delay in walking, climbing stairs, or riding tricycles, may have a mild cerebral palsy that was unrecognized earlier. A child with delayed or deviant language development may have a mild degree of retardation or specific language or learning disabilities. Recognition is based upon the fact that the child cannot function as well as a normal child in one or more areas.

All of these conditions are readily and accurately diagnosed by a multidisciplinary approach and reasonably accurate plans for intervention should be established and put into effect even before the child is of formal school age. Again, recognition of the possibility of an existing handicapping problem must occur before definitive diagnostic procedures can be set in motion.

During the school years the teacher enters the scene. The child is asked to carry out his normal activities under more structured conditions, under close observation and often in a competitive situation. It is therefore a fact that the teacher can measure the global functioning of the child very accurately, and in many cases may be the first person to recognize a handicapping condition. Recognition can be quite definitive and sophisticated, and a very accurate diagnostic profile can be provided by an observant teacher, which can play an important part as a component of the multidisciplinary evaluation.

(5) Adolescence Diagnostic Procedures

The same factors seen in childhood apply to adolescence with the major addition of some new and unique attitudes.

The effect of environmental factors over the prior years may introduce additional difficulties, particularly in the learning area. This may sometimes serve to make diagnosis more complex and intervention more difficult. By this time, also, the central nervous system has achieved full maturation and any handicapping condition in this system has matured to its final pattern. The result can be years of lost functioning and learning which make it difficult to "catch up."

Other acquired diseases or disabilities may also have occurred over the past 12 or 13 years of life and may have led to a new group of handicapping conditions. Those due to insult to organs or systems from trauma, infection or other illnesses may now have appeared. Transient hypertension is not an uncommon finding in adolescence, but our present state of knowledge does not tell us the long-term significance of this.

By adolescence many of the milder childhood seizure disorders may no longer be an evident problem, and more significant patterns of seizure activity, organic brain disorders, or behavioral problems are evidenced.

A new set of emotional and behavioral patterns has also occurred to compound existing handicapping conditions. Perhaps the most important factor here is the adolescent's newly-discovered self-consciousness which may make him look at an old handicapping condition in a new and less favorable light. These changes in attitude cannot be over-emphasized, and their recognition is a most important part of the diagnostic process. Early intervention against these changing patterns of diminishing self image is vitally important here.

This is also the age of preparation for a work career when the vocational rehabilitation professional enters the scene to diagnose and intervene alongside the teacher. Vocational rehabilitation diagnostic procedures tend to be more specific and largely functional.

(6) Adult Life Diagnostic Procedures

With the passing of adolescence, diagnostic intervention changes in quality. In the adult, the internist replaces the pediatrician, and the health center replaces the well baby clinic. Employers may replace teachers as diagnosticians and co-therapists.

Diagnostic procedures at this stage revert to largely medical assessment of symptoms and signs as the maturational processes are replaced by finite disabilities.

Increasingly, handicapping conditions due to chronic disease or certain acute processes such as those due to injury are added to the list. With increasing years, a new group of disorders are seen that are secondary to wear and tear of certain systems. Cardiovascular disease may produce functional impairment either generally or locally. Hypertension is a handicapping disease and may cause acute processes elsewhere, such as stroke. Chronic respiratory disease may impair function. Malignant disease may occur and handicapping conditions may follow radical or pallative therapy. Vision and hearing may become impaired as an acquired condition due to various diseases. All of these conditions may lead to handicapping conditions.

In all these cases, primary diagnosis is likely to be medical, but the assistance of many other professionals such as the physical therapist, occupational therapist, audiologist or speech therapist, to name a few, will be needed both for complete diagnosis and early intervention.

EARLY INTERVENTION

Intervention is a different process from diagnosis. It is hard to separate the two because intervention tends to follow closely after recognition and diagnosis. Although purely diagnostic facilities exist, they must either concern themselves with the next procedure of intervention or have adequate access to appropriate providers of intervention services.

The earlier the diagnosis is made, the more potential there is for early intervention and for the prevention of further disability.

Early intervention can be regarded as consisting of three primary processes: (1) To prevent further physical disability due to a disease process; (2) To produce actual improvement in the handicapping condition itself by medical or other means; and (3) To introduce helping procedures where the disability is already established.

(1) Intervention to Prevent Further Disability

This is largely a medical prerogative that involves a multitude of procedures for different conditions. An example of disability prevention by early intervention is the early treatment of hypertension. Hypertension, in its early phases, is a relatively mild handicap; if not treated, it may lead to vascular problems such as stroke, which in turn produces a major handicapping condition. Another example is the care of the retarded child where early social and educational intervention can help the child achieve his or her potential. Failure to intervene at any early stage may lead to additional impairment in learning and an eventual state of mental retardation more serious than the one with which the child started. This has been one of the consequences of institutionalization in which numerous studies have shown a progressive decrease in measured ability.

(2) Intervention to Produce Improvement in the Handicapping Condition

In many motor disabilities, such as stroke, failure to intervene early may delay or actually prevent the full implementation of normal recovery. Most motor conditions treated early with adequate physical therapy and other means are likely to be ultimately less severe than those treated late. The earlier the intervention, the better the prognosis. Total failure to intervene can lead to a worsening of the condition with increasing immobility and even irreversible changes.

(3) Intervention to Help the Established Disability

There are limits to both the amount of prevention and the amount of treatment possible in many handicapping conditions. The very definition of a handicapping condition implies this. One of the more important aspects of treatment of the handicapping conditions, therefore, is recognizing common residuals of the condition and helping to compensate for the problems involved. It is postulated that the earlier this is done, the better the eventual results.

Such intervention can be divided into two aspects. The first is that of working with the physical dimensions of the handicap, whether they be motor, learning, perceptual or other. The second is that of working with the psychological problems of the person who has the handicap. This involves helping the individual to resolve attitudes and feelings, and encouraging a positive approach to the problem. It also involves consideration of society's attitude to the handicapped person, which can be an even more difficult problem.

Direct work with the disability is largely the job of medical and/or allied medical professionals. Working with the attitudes, feelings and emotions of the individual is much less formalized because of the greater variables seen in human behavior. The most important aspect of early intervention may be that of helping the handicapped person to adapt to his problem and helping him to maintain his place in society with a positive approach to life. This type of intervention must take place as early as possible. Many of the physical problems of a handicapping condition can be helped, even after a lapse of time but improper attitudes, once developed in an individual, may be much harder to change.

The attitudes of society toward the handicapped are even harder to change, perhaps for the very reason that they have existed for so long. The word "Epilepsy" has existed for 2,400 years and has had time to collect many unpleasant connotations. Such attitudes usually stem from the worst aspects of the disorder and usually reflect the fear and ignorance of those who hold the attitudes. Such attitudes toward the handicapped may also interfere with social interactions and hiring practices.

It is a sad commentary on man's inability to control his own fears as well as a reflection of his ignorance that in this modern age we have to legislate tolerance. The laws, unfortunately, do not solve all problems related to tolerance, and sometimes they create new problems. Perhaps less emphasis on laws and more emphasis on public education would provide better understanding and more positive results in overcoming the stigmas associated with certain disabilities.

PROFESSIONAL INVOLVEMENT

(1) The Physician

Traditionally, as handicapping conditions are basically medical in origin, the physician or surgeon has been the main professional involved in both diagnosis and early intervention. In many handicapping conditions, continuing medical problems make this an essential involvement.

Furthermore, in many instances the physician has the advantage of a broader base of knowledge of the patient, the family, and handicapping condition. For example, in mental retardation, the physician may not know as much about some functions as the psychologist or the educator, but he can look at the total situation including problems in the family, the need for genetic counselling, the behavioral aspects of the condition including the possible use of medication, and associated medical problems such as visual or hearing deficits.

For this reason it can be postulated that the physician should be an integral member of a multidisciplinary diagnostic team, recognizing that his expertise is insufficient on its own.

One of the disadvantages the physician suffers from is that his training is usually largely in acute medicine, and much less in the handling of chronic disease or handicapping conditions. At this time only a limited number of physicians have acquired knowledge and trained themselves in the area of longitudinal care of handicapping problems.

Further training of physicians in the area of handicapping conditions is important for both diagnosis, early intervention and treatment of handicapping conditions.

(2) The Nurse

The nurse is frequently the allied medical professional closest to the physician. If specifically trained, the nurse may initiate or facilitate early identification and early intervention. In the public health field, she is in the front line of community medicine and is closer to those in need of help than any other professional. Although emphasis in the public health field may have been on providing care to the community, it is suggested that the public health nurse has an even bigger potential for helping in the early screening for medical conditions and, particularly, for chronic handicapping conditions. The well baby clinic is a place where 90% of developmental disabilities can be recognized by early clues before the child has reached school age. This potential needs to be encouraged.

The public health nurse is often likely to be the first professional in a position to identify potential handicapping conditions.

(3) The Nurse Practitioner

Nurse practitioners and other medical assistants can be valuable assistants in both diagnosis and treatment because of the nature of their extra training.

(4) The Social Worker

Many social workers are in the front line for early recognition of medical conditions, especially handicapping conditions. The higher risk of handicapping conditions in the lower socio-economic group makes the social worker in the Department of Social Services an individual who can play a very important part in early recognition. She may have no medical background, but can recognize a disability per se and should then know where to seek the appropriate diagnostic help.

(5) The Teacher

In the school-age child, the teacher is a valuable professional for early recognition of handicapping disorders. Many times it is the teacher who will recognize a developmental problem, such as a learning disability, not previously suspected by parents. A number of teachers have recognized "petit mal" seizures in a child before a parent has realized the significance of the child's staring spells. Within the structured program of a classroom, the teacher may recognize motor disabilities and other problems which are not so evident in the outside world. Communication problems often are first pinpointed by the teacher. Although the teacher may have no medical knowledge, often she can recognize the problems and refer her charges to appropriate health care resources. As a professional, she also may have skills to carry out educational diagnostic procedures.

(6) The Vocational Rehabilitation Counselor

The Department of Vocational Rehabilitation can intervene to provide employment-related services for certain handicapped individuals. There is no legalmandate and no precise legal age for this, but since emphasis is on work training, 15 years is usually the minimum age of involvement. Diagnostic procedures usually will have preceded this intervention, but the Vocational Rehabilitation Counsellor will make further diagnostic studies which will emphasize practical

skills. There may be a tendency to select candidates with minimal handicaps based upon the quota system and because of the emphasis on work placement. Vocational rehabilitation is technically a branch of education and must work with the vocational programs provided by most school systems. Unfortunately, emphasis on academic achievement has held back the adequate development of vocational school programs to help mildly handicapped individuals.

(7) The Specialized Professionals

Many professionals who are trained in specialized areas will work with the handicapped. They include those who work with vision, hearing and speech; and physical therapists and occupational therapists working with sensory motor function. These professionals may play an important part in the creation of a diagnostic profile and must clearly use an interdisciplinary approach in order to coordinate their efforts. Too often a multiply-handicapped individual is recognized and treated for his major disability while minor problems are missed.

(8) The Parents

It must be recognized that parents are experts in their own right, and are the closest to the child.

A parent may be the first to recognize a handicapping condition in a developing child. Unfortunately, parental emotions may not allow the acceptance of the disability, and counseling may be needed. Too often, a parent does recognize a difference in a child, only to receive unwarranted reassurance from a professional such as, "He will grow out of it."

Parents are an integral part of the early diagnostic team and also part of the early intervention team.

SERVICE PROVIDERS

Traditionally, the primary unit concerned with the handicapped individual is the medical clinic. Early diagnosis is more often established in an acute medical clinic, and the individual subsequently referred for specialist care. Such medical clinics include university based clinics, general hospital clinics, clinics set up by community health services, and private clinics and medical offices. Specialty clinics are also available.

The health departments of municipalities are another site for such clinics. From time immemorial there has been potential conflict between the private and public sectors of medicine, but in areas where private facilities cannot afford to offer free care or (often overlapping) are not readily available, the health department must reach out to provide diagnostic and interventive services.

VOLUNTARY ORGANIZATIONS

Mention must be made of the multitude of organizations representing different handicapping conditions. These include specialized organizations such as the organizations for the Blind, the National Association for Retarded Citizens, specialized organizations such as the National Foundation/March of Dimes, and the National Easter Seal Society for Crippled Children and Adults.

Some of these organizations serve largely to support research, but some provide or purchase services, mostly therapeutic, but occasionally diagnostic as well as preventive. Many of these organizations have local units which are in part parent motivated and parent organized, and have a significant input in their own areas.

DATA COLLECTION

An important aspect of diagnosis is the collection of data. The statistics quoted earlier serve as an indication of the fact that the true number of handicapping conditions existing in this country is largely a matter of conjecture. Actual numbers are needed so that services can be planned. Data collection at the federal level is of some value to those planning service at a community level, but data collection at a state level would be more relevant.

There are, however, a number of problems involved. One is that of ensuring confidentiality. A lot of opposition to data collection systems has come from professional services concerned with maintaining this confidentiality. Another problem is that of ensuring that a high enough percentage of cases are reported. Unless this happens, reliance on the figures could tend to produce a gross underestimate of the needs and endanger the provision of adequate services. Planning for optimal utilization of services is a must.

One solution would be to require the mandatory reporting of handicapping conditions. Problems of infringement of individual rights and concepts of confidentiality must be considered in any reporting system.

SUMMARY

(1) Handicapping conditions are basically part of a spectrum of chronic diseases and impose an extra burden on handicapped individuals.

(2) It is a generally accepted medical proviso that the earlier an intervention strategy is begun, the better will be the ultimate result of the treatment.

(3) Early intervention implies early recognition and this must, in turn, be followed by early diagnosis. Diagnosis does not mean applying a label to a condition but rather a measure of the abilities and disabilities of the individual concerned.

(4) Handicapping conditions cover many different systems of the body, and may sometimes be multiple. Because different professionals specialize in working with the different systems, a multidisciplinary approach is essential.

(5) It is important to assess the whole individual, not just the presenting problem. The overt handicap may be only the tip of the iceberg.

(6) Some type of data collection system is necessary to plan and deliver needed services.

(7) Multiple legislation is developing at Federal and state levels, often to demand the carrying out of what should be commonly accepted practices. Unfortunately, this legislation does not always take into consideration what has already been done, or even what should be done. In view of the complexity of the increasing legislative procedures, finding solutions may be difficult.

(8) Legislation may not always be accompanied by adequate funding. It is possible that with increasing early recognition, more needs for intervention are produced. The result can be the creation of an identifiable population of handicapped individuals who cannot be served because of insufficient funding and lack of trained personnel, equipment, and resources.

(9) Many groups of professionals and organizations must remain involved with handicapping conditions and work together to provide better services. With increasing needs, there may develop a real shortage of available professionals, particularly in the area of developmental disabilities.

(10) One of the more important aspects of early intervention is that of dealing with abnormal and destructive attitudes. These include possible reduced self-image by handicapped persons which can prevent them to achieve their full potential. They also include the abnormal attitudes of society which often, because of fear or ignorance, rejects the person who is different.

PREVENTION OF DISEASE AND DISABILITY

Awareness Paper Prepared By

Winfred F. Malone, Ph.D.
National Cancer Institute
Bethesda, Maryland 20014

ACKNOWLEDGEMENT

The White House Conference on Handicapped Individuals wishes to thank the following individuals who have contributed significantly to this document:

Edward C. Keller, Jr., Ph.D.
Professor, Department of Biology
West Virginia University
Morgantown, West Virginia

Eugene J. Taylor
Secretary-Treasurer
World Rehabilitation Fund, Inc.
New York, New York

Mrs. Winfred F. Malone
who typed the manuscript for her husband

TABLE OF CONTENTS

	Page
Introduction	65
Discussion of the Problem	66
Current Conditions	67
Chronic Diseases	67
Physical Disability	67
Mental Illness and Mental Retardation	67
Exposure of Public to Hazards	68
Chemical	68
Physical and Environmental	69
Gun Control	69
Substance Abuse	69
Alteration of Personal Behavior	70
Delivery Systems for Prevention	70
Transfer of Technology	70
Public Education in Prevention	70
Professional Education in Prevention	70
Overall Strategies for Reducing Disease and Disability	71
Costs and Benefits	71

INTRODUCTION

This paper will enumerate major diseases contributing to disability in the United States and will discuss factors which can prevent such disability. Consideration of these preventive aspects should result in the development of a set of priorities for restructuring existing situations to maximize protection to the public from disease and disability. The suggested strategies should create policies and obligations to replace present situations which permit specific conditions, commodities, services, products, activities or practices to pose a direct hazard to health and physical well being.

In spite of the 118 billion dollars spent on health care during fiscal year 1975, our health indices remain unsatisfactory.[12] In some respects, such as death rates for young and middle-age men, these indices actually worsened during the 1960's. Major causative factors relate far more to environment and to individual behavior and lifestyle than to health care as such. Therapeutic and rehabilitative medicine in some instances has reached a point of diminishing returns. Clearly the time has come for basic rethinking of national health priorities, and transfering a more meaningful proportion of health resources to strategies other than health care, which is the most expensive strategy and the one that has monopolized health resources for the last two decades. Preventive activities will require a major reemphasis. The Federal government has special responsibility related to economic and health factors to provide essential leadership, including the channeling of adequate national resources into preventive research, education and control.

Dr. Howard A. Rusk, Professor and Chairman of the Department of Rehabilitation Medicine, New York University School of Medicine, has stressed many times that rehabilitation is the "third phase" of medicine. The first phase is, of course, "preventive medicine", the second phase "curative medicine and surgery."[1] Each of the three phases of medicine, however, is interrelated.

The World Health Organization at its Assembly in June of 1976, voted for a new program of "disability prevention and rehabilitation." It pointed out that "medical care in the past has been more attentive to the problems related to mortality and immediate phases of morbidity than to the less traumatic problems of long-term impairment and permanent disabilities. . . . A better understanding of the causes and consequences of disability, and how it may be prevented" or ameliorated is particularly needed.[2] This new program has as its overall objective the introduction of services aimed at reducing the global disability problem and with much greater population coverage than heretofore achieved. Obviously it is far less costly to introduce measures of prevention, and thus eliminate a substantial amount of disability, than to repair the disability after it occurs.

All persons interested in health services recognize the importance of injuries resulting from the automobile, and more particularly the motorcycle; the effects of the prolonged use of tobacco, alcohol, and drugs upon the individual; the hazards of places of employment; and the damage caused by environmental pollution of all sorts. All of these threats represent a major contribution to disease and disability in our society. We know from research that certain prevention aspects can substantially reduce the hazards of disability resulting from these environmental forces. We know we can reduce disease and disability by developing methods to minimize the exposure of the public to various hazards by introducing certain techniques which reduce the hazards of the environment, such as fluoridation and seat belts; and improved techniques for early detection and early treatment to minimize the potential damage from hazardous forces in the environment such as excessive noise.

Currently a great reduction in disabilities and handicapping conditions has come from curative health services. This has been largely the result of the dramatic developments of the antibiotic age. Prior to this, life-saving occurred on an almost "one-to-one" ratio between the physician and the patient. With the development of antibiotics, however, life-saving became a matter of mass proportions.

Fifty years ago one rarely saw an adult with severe cerebral palsy. Such persons usually suffered from respiratory insufficiencies and died of pneumonia or other respiratory diseases and complications before they became adults. This is all changed now with antibiotics which effectively control pneumonia.

Fifty years ago a person who broke his back or his neck was doomed to die. Today, however, we have hundreds of thousands of persons with spinal cord injuries who have been saved; and, although they continue to function from wheelchairs, they have proven to be effective citizens and workers. Studies have shown that the

life expectancy of the person with a spinal cord injury who understands his condition and seeks medical attention regularly is about the same as that for an uninjured person of the same age and sex.

It is true that, "Each time we make a medical advance, we create a rehabilitation problem." Major reductions in disabilities and handicaps cannot be expected from future developments in curative health services alone. Future progress will have to come largely from the alterations in the environment and life style.

Modern disease and disability prevention is not confined to doing things for and to people, such as insuring them of safe food and water and immunizing them against infectious disease. As life becomes more complex, individuals must have increased knowledge about the personal health risks and the alternatives and changes in attitudes and actions that can bring about more healthful living. Modifications of behavior and changes in environment are prime areas for improvement.

It is quite probable that the major focus of the White House Conference on Handicapped Individuals will be on curative medicine, rehabilitation, employment, and the social role of handicapped individuals in the society. We should not, however, overlook the fact that the perpetuation of the same "classic" attitudes toward prevention will mean not only a continuation of the present incidence of disability, but even a greater incidence of disability as life becomes more complex. A major thrust of this Conference should be the development of national and local strategies for the rights of all citizens to full and equal protection against disease and disability.

DISCUSSION OF THE PROBLEM

Prevention is the logical consequence of the ethical goal of minimizing the numbers of persons who will become diseased and disabled. The only way to minimize these adverse events is to prevent the occurrence of damaging exchanges or exposures in the first place, or to seek to minimize damage when exposure cannot be controlled.[3]

Historical Perspective

From the last decades of the Nineteenth Century to the present there has been an increase of almost 30 years in the average life expectancy of persons in the United States. The increase is primarily due to a decline in infant and child mortality; one-third of the increase is attributed to reduction in mortality of persons under 25 years of age.[4] Prevention of communicable diseases has been another prime factor. We have developed an awareness of maternal and infant health, nutritional deficiencies, the impact of dental disorders, and more recently occupational and environmental health.

Central to any of the earlier programs was the concept that any disease was preventable. Health departments became concerned primarily with the control of communicable disease through environmental sanitation. In the early part of the Twentieth Century, voluntary health agencies became involved in community education by advancing research, by calling attention to public health problems, and by promoting health legislation. Probably one of the most successful preventive programs was that of tuberculosis. The National Tuberculosis Association was formed in 1904 to mobilize community resources for the treatment and protection of cases by emphasizing environmental factors, such as clean air and personal nutrition, eradication of bovine tuberculosis, and pasteurization of milk. Tuberculosis control was aided greatly by the introduction of low-cost X-rays in the 1930's and the use of chemotherapy in the 1940's.

In November of 1976, the Albert and Mary Lasker Foundation presented an award to the World Health Organization in recognition of the first time in the history of man that a disease, smallpox, had become almost totally eradicated. The eradication of smallpox will save the United States in a few years more than the total contribution it made to the World Health Organization over the past 30 years.

The strategies and tactics in dealing with the prevention and control of tuberculosis and of smallpox have been used to handle other complex health problems. Two modes of action were developed and applied for preventive disease purposes during this century. One is the modification of human organisms through such procedures as immunization that prevents the introduction of disease into the body. The other is the alteration of the environment through water purification, pasteurization, reduction of air pollution, and addition of nutritives to food. The late Dr. Haven Emerson, one of the founders of public health, said over 30 years ago that public health had achieved the status of a purchasable commodity. If one were willing to make the invest-

ment, one could prophesy with a great deal of accuracy the benefits to be achieved by the public. As the garage mechanic in a television commercial says to the motorist, "Which would you rather do, buy it now for a few dollars or come in later for a really expensive repair job?"

CURRENT CONDITIONS

Chronic Diseases

It is obvious that the saving of lives in childhood, youth, early adulthood, and adulthood has contributed to increased numbers of persons in the older age groups. Two thousand years ago the average person lived to be around 25 and usually met death through some violent means. By 1900, life expectancy had been increased to 49; in 1950, it had risen to 67.

In 1950, the Associated Press asked some prominent older persons what they considered the most important happening of the first half of the 20th century. The late Bernard M. Baruch reported that it was not improved transportation, communication, atomic energy, or other technological advances, but rather the increased life expectancy during these 50 years that held the greatest implication for our nation.

The National Health Survey of the Department of Health, Education and Welfare reported that in 1974 there were an estimated 29,292,000 persons who were limited in their activities to some degree due to chronic disease and impairment.[5] This represents 14.1% of the civilian, non-institutionalized population of the United States. Limitation of activity was defined as inability to carry on the major activities of one's age-sex group, such as working, keeping house, or going to school. About two-thirds of all of the persons with limited ability are 45 years of age or older.

We know that new medical research, greater availability of and better results from medical care, improved nutrition, better housing, and other factors which contributed to the phenomenal growth and longevity in the past are going to continue. However, we cannot expect the results to be as dramatic in the next 10 to 20 years. Estimates by actuaries in government service and in the insurance industry indicate that the average life span will be increased to 75, but not much further. In contrast to the remarkable gains since 1900, longevity will remain fairly constant after the year 2000. Further savings in mortality must come largely from the control of cardiovascular and renal diseases, cancer, and accidents. These causes combined account for more than three-quarters of all current premature deaths.

Physical Disability

It has been estimated that about 10% of the world's population suffers from physical disability.[6] Some of these require only minor support, others need considerable support, and some are severely disabled. The age incidence of disability is significant; whereas the incidence of physical disability is less than five percent in the young and middle aged, it is about 25 percent in the elderly population.

The common causes of physical disability among the young are cerebral palsy, spinal cord lesions, and fractures; in the middle aged, rheumatoid arthritis, multiple sclerosis, and degenerative neuromuscular disease; in the elderly, osteoarthritis, strokes, amputations of the lower limbs, and cardiorespiratory disease. Through primary prevention, a number of these conditions can be prevented. Through secondary prevention, a reduction in the degree of resulting disability can be accomplished.

With the word "disabled" we think of different people and different conditions, for disablement ranges from those who need total care for their very existence to those who think of themselves as disabled because they have an ugly disfigurement or who are unable to enjoy the totality of life experiences available to the able-bodied. There are those who are physically fit and mentally disabled, and those who are mentally fit and physically disabled, those who are handicapped from birth or childhood, and those who become handicapped once they reach adult life.

Mental Illness and Mental Retardation

It is estimated that there are more than six million persons who at some time in their lives will be considered mentally retarded. In about 80 percent of this population there is no identifiable gross pathology of the central nervous system, and early behavioral and developmental signs are difficult to detect, which hampers identification efforts. This group is more often found among populations of economically depressed urban and rural areas. There is need for research to determine the etiological factors responsible for these conditions resulting in mental retardation

and the development of programs for primary and secondary prevention. The Milwaukee Project of the University of Wisconsin has been instrumental in pointing out the great need for social, educational, and rehabilitation programs. Prevention of mental retardation may well have deep roots in the social and nutritional ambience of the prenatal child. This is a pathway for the future of investigations on the prevention of mental retardation.

The number of individuals under treatment for mental illness has grown tremendously in recent years. In 1955 there were 1,675,000 persons under treatment for emotional disorders; by 1971 the figure was 4,038,000. Our present lifestyle may be creating additional mental stress. Divorce rates have risen dramatically. Because of their great mobility, people no longer rely on the extended family for psychological support. The changing occupational profile, which appears to create insecurity in all levels of the working population, may be playing a role in increased mental illness. A study of disability insurance benefits awarded by the Social Security Administration from 1959 to 1962 to men age 65 and under reveals that a higher percentage of awards were made to accountants, auditors, and other professionals than to blue collar workers.

Some of the rise in the number of patients seeking psychiatric help may be due to the growing acceptability of professional treatment. In the past, people with problems tended to go to their friends or their ministers; today they are more likely to go to their physician, to a mental health clinic or directly to a psychiatrist. A careful analysis of the current social and economic stress trends may result in reorientation of our national approach to mental health problems. This could be a major step in the prevention of emotional disability in both our child and adult populations.

EXPOSURE OF PUBLIC TO HAZARDS

Chemical

About 80 percent of the U.S. population lives in urban areas and is selectively exposed to power production and industry. Power production has been increasing at more than 5 percent per year, and some 12,500 chemicals with toxic products are now in industrial usage. Global effects have been predicted from the operation of jet planes in the stratosphere, including the production of various chemical by-products and the resultant reduction of the ozone layer. Environmental agents have their greatest impact on non-fatal diseases, although they account for many fatalities. Major cardiovascular diseases account for 50 percent of the deaths in the United States, of which a large percentage is premature. There is evidence for environmental factors in about 80 percent of these cases. Nutritional factors, such as high cholesterol diets, as well as cigarette smoking and occupational hazards, including stress and exhaustion, have been reported to play a role in accelerating cardiovascular disease. Homicides, suicides, and accidents account for 8 percent of deaths and a high percentage of disability, primarily in the younger age groups. Essentially, all injury deaths involve environmental agents or conditions. Thus, a large number of premature deaths are related to environmental factors, and preventive measures directed toward control of these factors offer the greatest potential in terms of both mortality and disease, injury, and disability.

There are over 14,000 occupational injuries in this country each year, and over 100,000 deaths each year that are associated with occupational factors. Prevention of these problems would appear to be conceptually simple, that is, to ascertain the health effects and the measures of exposure, determine the conditions or exposures related to high disease rates, and reduce or eliminate these conditions. Considerable time, effort, and funds must be forused on these problems.

Cancer accounts for more than 18 percent of all deaths in the United States.[5] Environmental factors, including cigarette smoking, diet, occupational exposure to carcinogens, and other personal or hygienic factors, are believed to be related to a large number of these cases. Causes of cancer and respiratory disease in the work environment need to be examined more vigorously. More attention needs to be given to medical records, death certificates, cancer registries, and large group health plans. Primary prevention strategies must involve specific training and education programs devised and tailored to each type of industry. Workers should be apprised of occupational health hazards and taught how to handle, monitor, and control these hazards. There must be greater understanding of the causes of and measures to prevent occupational disability.

There is a variety of diseases which develop slowly with advancing age and involve progressive damage and structural disorganization of the affected organs. One example is arteriosclerosis, the etiology of which is obscure, for which two environmental factors are implicated, namely cigarette smoking and high dietary cholesterol. An intensive effort is now being made to determine the role of other environmental factors, such as mineral composition of drinking water and occupational exposure to chemicals such as carbon disulphide.

Other diseases in which environmental factors have been identified or implicated include cirrhosis (alcoholism), chronic bronchitis and emphysema (cigarette smoking, air pollution); and chronic diseases of the kidney (drug ingestion and trace metals), endocrine organs (nutritional factors), nervous system (trace elements), musculoskeletal system (repetitive trauma), and hematopoietic system (drugs and chemicals). Research into the causative biomedical factors related to degenerative diseases is hampered by the chronic nature of the problem and the tendency to focus on more immediate problems. Long-term efforts are required to determine the role of the environment in the etiology of chronic diseases and disability, and the implementation of research for their prevention.[7]

Physical and Environmental

In the United States, injuries are the leading cause of death from age one through the beginning of the fifth decade of life; the median age of persons dying of injuries is 38 years. Between the ages of 18 and 65, the number of working years lost because of injury deaths approximates the total for cancer and heart disease combined. In 1970, injury deaths, excluding military and non-military injury deaths outside the U.S., totaled 160,000; this included 23,000 suicides and 17,000 homicides. The largest number of injury deaths were associated with motor vehicles (55,000), firearms (25,000), falls (17,000), poisonings (12,000), drownings (8,000), and non-vehicle fires and burns (7,000).

Among the aged, injuries are primarily due to non-motor vehicle accidents such as falls and fires.[8] [9] During the most productive years of life, and in many countries during childhood as well, motor vehicle fatalities comprise the largest category of injury deaths. Increases in the numbers and use of motor vehicles have been accompanied by dramatic increases in the number of deaths and injuries, especially among teenagers and younger adults. Significant numbers of injuries and all fatalities from fires occur in homes. Specific health effects arise from exposure to such hazards as allergens, toxic gases, dust, inadequate heat, noise, electricity, and fire.

Prevention must include identifying those conditions in design of structures, transport vehicles, and roads which will reduce injury and disability. Standards must be adopted to protect persons from exposure to conditions that will result in disease and disability.

Gun Control

Homicide and suicide, and attempts thereof, are among the leading causes of death and disability in the United States.[9] Within the 15–24 age group they are the second and third leading causes, exceeded only by accidents. The cost of health care and rehabilitation for victims of shootings and the cost of law enforcement to protect against these shootings is obviously very high. Therefore, serious thought must be given to enforced gun control if we are to *prevent* the disabilities caused by the improper and unlawful use of these weapons.

Substance Abuse

Prevention of health problems associated with substances such as food, tobacco, alcohol, and narcotics and other drugs is particularly difficult because of the lack of agreement on certain criteria for distinguishing use from abuse. The abuse of food is defined as the consequences of obesity, for example, cardiovascular and renal disease and diabetes. About 80 million Americans are 20 pounds or more overweight; and the prevalence of obesity has increased as exercise has been divorced from most occupations, as well as household and transportation activities.

Alcohol prevalence surveys estimate there are 6.5 million heavy drinkers. A number of disorders are related to alcohol abuse, including vitamin deficiencies, gastrointestinal and metabolic diseases, neurological and psychiatric disorders, and cardiovascular and hematological conditions.

Current data indicate that 600,000 to 800,000 persons[10] are addicted to narcotics which can lead to endocarditis, hepatitis, and cardiac failure as well as the inability to work productively, the

shift toward crime, and personal and social dependence on these substances.

True prevention will require widespread and comprehensive public health education on each of these danger signals of future handicapping conditions.

ALTERATION OF PERSONAL BEHAVIOR

Chronic diseases appear to be more dependent on personal behavior. Thus, an important means of preventing current health problems is through influencing daily habits of people. Education is the major component of primary prevention. Examples include counseling for modification of diet to reduce intake of calories and saturated fat, cessation of smoking, reduction in alcohol consumption, exercise to combat physical inactivity, accident prevention, and control of genetic disorders, and family planning.[11]

DELIVERY SYSTEMS FOR PREVENTION

In addition to the above components of primary prevention influencing personal health habits, scientific and technological advances have provided considerations for secondary prevention programs. Technical means have been developed for surveillance of conditions important to health and the identification of deviations that often evolve into disease. Procedures for detecting abnormal conditions need to be evaluated to determine the extent of their usefulness, and a major effort must be made to incorporate these procedures and knowledge into physical and behavioral risk factors which become an integral part of personal health services.

TRANSFER OF TECHNOLOGY

Recent history indicates that it takes from 5 to 25 years for a technique, once developed, to become widely accepted in the health care delivery system. This lag between development and general use should be reduced by more prompt and systematic evaluations so that new procedures can be instituted promptly if they are found to be meritorious. To incorporate preventive technology, we must determine precisely what conditions are to be prevented by what procedures, by what means, and at what cost.

PUBLIC EDUCATION IN PREVENTION

Prevention education must be initiated in early childhood and continued throughout life, changing with the needs of the individual and keeping pace with newer health information and practices. Education calls for new initiatives on the part of health professionals, schools of public health, hospitals and other related facilities, school systems, organized labor, industry, consumer groups, mass media, the drug and appliance industries, and all levels of governments.[12]

Annual health examinations and counseling programs for executives are becoming more common as are periodic screening of "blue collar" employees. There are lunch hour lectures on a variety of health topics for "blue collar" and "white collar" workers. These and many other general maintenance and educational activities are currently taking place throughout American business and industry, but they have made only a dent in the general health care of American workers. The major culprits that hamper health education are individual ignorance, public apathy, commercial pressures, and the lack of any strong positive leadership on the part of either the government or the health profession. The latter must be part of the mandate emanating from this White House Conference on Handicapped Individuals.

PROFESSIONAL EDUCATION IN PREVENTION

The application of prevention must be part of the attitudes, knowledges, and practices of health care providers. Medical education still emphasizes and reinforces an orientation toward diagnosis and treatment of diseases brought by patients to medical practitioners. Medical education teaches physicians to deal effectively with manifestations of disease, and there is usually too little time for preventive approaches. The sense of responsibility for health maintenance must be sufficiently cultivated. A major task, then, in the area of prevention is to provide better professional education on prevention for physicians and other health care providers.

OVERALL STRATEGIES FOR REDUCING DISEASE AND DISABILITY

The general public itself appears ready, perhaps even more ready than health professions, to embrace preventive measures as an important part of their health regimen. The nature of financing health care exerts a substantial influence on how preventive services are actually used. Many health insurance plans specifically exclude preventive services for their benefits. Personal education and counseling are major components of primary prevention. The aim is the prevention of disease through influencing an individual's lifestyle. Another major element of primary prevention is prophylaxis, such as immunization, and fluoridation of water supplies. Secondary prevention through screening followed by early treatment will be very important in reducing disability due to many chronic diseases.

The goal of target and community programs is to identify individuals who are at risk, make them aware of the risk and tell them the steps they can take to reduce the risk, and, if symptoms are brought to light, direct individuals to appropriate care centers which must be readily accessible.

The application of a preventive procedure must alter favorably the history of the disease and reduce disability; the preventive procedure should be applicable and acceptable to the target population and easy to administer; follow-up with suitable diagnostic and therapeutic intervention should exist, be applicable and acceptable; and sufficient resources must be available.

COSTS AND BENEFITS

As previously mentioned national expenditures for health care reached 118 million in fiscal year 1975, or over 8 percent of the gross national product. With such a substantial share of resources going into health care, there is a widespread concern as to whether the overwhelming proportion of health expenditures should be directed to care and maintenance of the sick and disabled or whether more resources should be directed toward preventive strategies. One cannot determine the effect of allocation of resources to prevention in general; one must consider each particular program. But prevention *must* get a fair share if we are to influence health and handicapping disabilities in the future. We no longer have infinite economic resources; we have come to a time where we must set priorities in health care. There are many factors other than medical intervention which influence health status and health outcome. While it is difficult to assess the relative importance of these factors, we should at this time review what we know and what we can do in particular areas. The challenge here, then, is to indicate those areas which will reduce a problem without drastically increasing the total financial obligation.

Finally, our major objectives in all of the above considerations should be a lifetime for all individuals that is free from illness, injury and impairment; and an opportunity for each person to realize his full capacity for physical and intellectual growth.

BIBLIOGRAPHY

1. Rusk, Howard A., M.D. Rehabilitation, Excerpta Medica, Section IX, Surgery, Vol. 10, December, 1956.
2. WHO Assembly Resolution 19.37–EB–Working Document No. 1, 1976.
3. Beauchamp, D.C. Health Policy and Polities of Prevention. Abstracts. APHA Annual Meeting, APHA, Washington, D.C., 1975.
4. Rosen, G. Preventive Medicine in the United States in Historical Perspective. National Conference on Preventive Medicine., DHEW, NIH, 1975.
5. National Health: Vital and Health Statistics. Data from the National Health Survey, Series 10–No. 112. National Center for Health Statistics, 1974.
6. Burress, James R. The Human Concern, Committee for the Handicapped People-To-People Program, December 12, 1976.
7. DHEW.Theory and Application of Preventive Medicine in Personal Health Services. National Conference on Preventive Medicine. NIH, 1975 (in press).
8. National Safety Council. Accident Facts. Chicago, Illinois, pp. 60–61, 1975.
9. Klebba, A.J. et al. Mortality Trends for Leading Causes of Death, U.S. 1950–1969. DHEW, National Center for Health Statistics, 20–16, 1974.
10. Fogarty International Center and American College of Preventive Medicine. National Conference on Preventive Medicine Summaries and Recommendations, DHEW, NIH, 1975.

11. Stankard, A.J. New Treatments for Obesity: Behavior Modification, in Pray, G.S. Treatment and Management of Obesity, Harper and Row, 1974.

12. DHEW. Toward A National Policy on Health Promotion and Consumer Health Education. National Conference on Preventive Medicine, DHEW, NIH, 1975.

REHABILITATION AND TREATMENT

Awareness Paper Prepared By

Chester Swinyard, M.D.
Children's Hospital at Stanford, Palo Alto, California
Frank J. Menolascino, M.D.
University of Nebraska Medical Center, Omaha, Nebraska
Eugene J. Taylor
New York University College of Medicine
Anthony Staros
Veterans Administration
Gustav Rubin, M.D.
Richard LeClair
Department of Health, Education, and Welfare
National Institute of Mental Health
The Maternal and Child Health Program and
The Crippled Children's Program,
Department of Health, Education, and Welfare
The National Easter Seal Society for Crippled Children and Adults

ACKNOWLEDGMENT

The White House Conference on Handicapped Individuals wishes to thank the following individuals who have contributed significantly to this document:

Donald Harrington, Ph.D.
Office for Maternal and Child Health
Public Health Service
Health Services Administration
Rockville, Maryland

Ms. Valerie J. Bradley, Consultant
National Institute of Mental Health
Rockville, Maryland

Raymond L. Braham B.D.S., M.Sc.D.
President, Academy of Dentistry for the Handicapped
School of Dentistry, University of California, San Francisco, California

Arthur J. Nowak, D.M.D., M.A.
President, National Foundation of Dentistry for the Handicapped
College of Dentistry, University of Iowa
Iowa City, Iowa

TABLE OF CONTENTS

	Page
Introduction	77
Rehabilitation and Treatment	78
Treatment and Habilitation	80
Challenges in Mental Retardation	81
Mental Illness	82
Deafness	85
Vision—Eye Care and Treatment	85
Rehabilitation Engineering	86
Dentistry for the Handicapped	86
Conclusion	87

INTRODUCTION

Rehabilitation has been described as the third phase of medicine. Dr. Howard A. Rusk, Professor and Chairman of the Department of Rehabilitation Medicine, New York University School of Medicine has stressed this concept frequently and describes the first phase as preventive medicine, the second phase as curative medicine and surgery. The primary problem in rehabilitation is to prevent disability and the second is to minimize the effect on the individual. Unlike the hidden disabilities a physical disability is obvious. There was recognition of and action taken on the need for rehabilitation services for the physically disabled as early as World War 1. Rehabilitation has since evolved into a comprehensive art.

The National Health Survey of the Department of Health, Education and Welfare recently reported that in 1974 there was an estimated 29.3 million persons who reported they were limited in their activities to some degree due to chronic illness and impairment. This represents 14.1% of the civilian, non-institutionalized population of the United States, or 14.3 million males and 15.0 million females. About half of all these persons have major limitations in their ability to work, keep house, or go to school. About one of four limited persons is unable to carry on his or her major activity. Males constitute a higher proportion of persons who are unable to carry on major activities than do females.

A Concept of Physical Handicap

A physical handicap may be considered to be an aberration of physical development or function, occurring prenatally or acquired postnatally, which limits physical function and/or generates within the affected person feelings of inadequacy and anxiety with resultant impairment of intersocial relationships. When viewed in this context one becomes concerned with the entire gamut of physical handicaps ranging from a missing single digit to traumatic quadriparesis, and for normally or abnormally proportioned bodies of those 3-foot dwarfs or 8-foot giants whose extremes of growth failure or excess generate vocational and psychosocial problems. It also includes the abnormally proportioned child with Down's Syndrome, even though physical independence in activities of daily living might be possible. In other words, our concern extends beyond the boundaries of functional aspects of limb developmental failure or postnatal accidental loss. We are concerned with independence in living, the limitations on mobility imposed by society through architectural barriers; and with attitudes of others toward the handicapped person, which distort what should be equality on social interchange, and which actually lead to public discrimination in education, employment, and environmental exploration.

Magnitude of the Problem

Although we have cited statistics about major limitations, it is difficult to obtain accurate figures on the frequency of physical handicap because the varieties are so numerous. For example, Dr. McKusick's most recent catalogue of human diseases transmitted by Mendelian mechanisms of inheritance references nearly 2,400 separate types, most of which are accompanied by some aberration of physical development. One category of prenatally determined physical handicap includes those which reveal variable genetic influence that is described as multi-factorial or polygenic association. This group includes spina bifida, certain types of limb deformity, and many others. In another category there are from 3,000–5,000 newborns annually with physical dysproportion resulting from chromosomal defects. Another category one could place about 88% of the cerebral palsy patients whose brain injury resulted from a variety of prenatal causes in contrast to the 12% or 13% whose brain injury occurs after birth. Postnatal life accidents are an important cause of physical handicap during the first 20 years of life.

The enormous numbers of newborns who enter this world with a physical handicap plus additional thousands who acquire this distinction through accident or disease occurring after birth provoke contemplation about the biological and environmental hazards which affect all of us during prenatal and postnatal life. Such contemplation is relevant to this conference agenda since it points up the developmental fallibility of humankind as a species and provides the logic for allocating responsibility for the handicapping conditions.

Dynamics of Rehabilitation

Rehabilitation is a dynamic process of reestablishment of the disabled person's capacity to sense and participate in his environment and communicate with others; to adapt to the physical

world, which includes ability to tolerate physical energy expenditure while resuming activities of daily living; and to utilize fully intellectual, social, and vocational potentialities. The rehabilitation process assumes the primacy of the disabled individual and the development of a program for treatment, personal help, and guidance designed to meet his needs.

Resources for the Handicapped

Public agencies provide or purchase programs in family planning, early detection, treatment, surgery, dental care, equipment/appliances, vocational training and placement according to the policies and funding allocations of the State. The major agencies are State Crippled Children's Services, Maternal and Child Health, and Vocational Rehabilitation. Private hospitals, veteran's administration hospitals, and community rehabilitation centers operated by voluntary agencies such as the Easter Seal Society and United Cerebral Palsy have pioneered and continue to be the primary resources for rehabilitation services. Access to services remains a problem in many areas.

Varieties of Professional Care Organizations

If one bears in mind the diversity of chronic diseases whose commonality is physical handicap, it becomes evident that no single physician is capable of providing the diverse types of specialized medical care required; and the special skills of every medical specialty are essential to a comprehensive medical care program. Furthermore, all allied medical professionals including geneticists, occupational and physical therapists, special educators, and vocational counselors are vital to comprehensive rehabilitation programs.

The organizational structure in which these diverse health care services are provided might differ markedly. For example, a group of physicians and allied medical personnel functioning in a university teaching medical center, a free standing children's hospital, or a large community hospital are more likely to have available specialized instrumentation and requisite biochemical laboratories which are capable of precise diagnostic evaluation and certain types of technical follow-up care. For example, a new non-invasive technique to determine ventricular size can only be available in institutions able to devote $750,000 to a single piece of equipment. However, this environment does not guarantee coordinated comprehensive care because, to a large degree, such care is greatly dependent upon the spirit of cooperation and intercommunication which exists within the group.

REHABILITATION AND TREATMENT

Rehabilitation is society's unique process of restoring the dignity of its disabled members and of harvesting the products of their talents. It involves the utilization of recognized medical, psychosocial, and vocational services singly or in coordinated combination to meet the requirements of the physically and mentally handicapped.

Rehabilitation of the disabled, the responsibility of the involved individual, his family, and his community, calls for planning, action, and personal motivation. Rehabilitation requires the combined skills of physicians, nurses, physical and occupational therapists, social workers, psychologists, vocational counselors and teachers, recreation therapists, and many others.

Many leaders in medical rehabilitation have expressed the opinion that a major part of medical rehabilitation procedures can and should be carried out by the general practitioner or specialist responsible for the patient's primary medical care, and that these procedures should be an integral part of such medical care. Dr. Rusk[1] says this approach is essential if any substantial gains are to be made in preventing further deterioration and increased disability among the great majority of our sick and injured. For it is in physicians' offices and general hospitals that the overwhelming percentage of our medical care is given. There has been a substantial growth in such services by the general hospital where services can be brought to the patient at the earliest possible time so that damaging physical, emotional, social and vocational sequelae of the acute disease process can be alleviated or minimized. It is more costly to ignore disability than to provide an early aggressive program of rehabilitation that restores the individual to the highest possible level of physical, economic, social and emotional self-sufficiency.

Community Rehabilitation Centers

From the standpoint of continuing care these Community Rehabilitation Centers provide an invaluable national resource in rehabilitation.

While there are publicly and privately sponsored facilities, many of these centers are operated by voluntary groups such as the Easter Seal Society and the United Cerebral Palsy Association. Many of them provide comprehensive rehabilitation services and obtain technical, diagnostic evaluation through affiliation with or cooperative agreements with medical centers. Some of them provide selected therapeutic services, obtain consultations from community hospitals and receive referrals from larger centers. The variable emphasis of the smaller treatment centers precludes a comprehensive analysis, but such rehabilitation centers often operated by voluntary agencies provide an indispensable asset to the national rehabilitation effort. Most of these smaller centers offer out-patient services and are strategically located where families can obtain conveniently services with less disruption of family life. In smaller communities these rehabilitation centers often have closer relationships with other community health agencies than do some of the units in metropolitan medical centers, particularly with reference to specialized educational programs. Close interagency cooperation is as important as the intramural cooperation within a large center.

There is a justifiable tendency by some state Crippled Children's Services or other agencies to sponsor special clinics for selected types of physical handicaps in medical centers. This in no way diminishes the role of the smaller community rehabilitation centers because the central agency receives patients from a wide geographic area and is dependent on the local voluntary agency sponsored community center to provide day-to-day medical and rehabilitation services.

Maternal and Child Health Services

The Maternal and Child Health programs of the Department of Health, Education and Welfare (HEW) have helped to extend and improve health services for mothers and children, especially in rural communities. These programs are designed to reduce infant mortality by providing maternal and child health care, emphasizing preventive services in low income areas.

Maternal and Child Health programs were originally involved primarily in providing preventive health services. Currently the programs are focusing on treatment services to assist states in the delivery of curative and clinical services, as well as health care services for high risk mothers and their children.

Activities on behalf of mothers and children and, specifically, crippled children have evolved and expanded as national awareness of problems grew and as new medical technologies developed. In 1951, Regional Centers for the treatment of congenital heart disease were established; in 1963, in an attempt to reduce infant and maternal mortality and the incidence of mental retardation in high-risk groups, maternity and infant care projects were initiated; in 1965, children and youth projects were begun; newborn intensive care projects were added in 1967; early detection, expanded outreach, and dental care were added to under Title V in 1967; and in the early 70's, family planning programs were included in the service programs provided to mothers and children. Congress, through Public Law 93–53, directed conversion of various special project grants to a formula grant program by July 1, 1975 including those for Maternity and Infant Care, Children and Youth, Dental Care, Family Planning, and Intensive Infant Care.

Formula grants are awarded by HEW to state crippled children agencies to locate children who are crippled or who have conditions that could lead to crippling; and to provide them with medical, surgical, and other necessary care and services. Every state has a crippled children's services program, and state law either defines the crippling conditions to be included or directs the crippled children's agency to define them. All states include children under 21 years of age who have some kind of handicap that needs orthopedic or surgical treatment.

As is the case with the State Maternal and Child Health Services program, each state Crippled Children's Services program must be under the direction of a physician and must comply with federal regulations to assure (1) a high standard of care, including high standards for those personnel and facilities which are to be used in the provision of services; (2) the provision of comprehensive health care services to be provided are comprehensive in nature; and (3) the development, strengthening, and improvement of standards, techniques, and services.

Problems Related to the Treatment and Rehabilitation of the Physically Handicapped

1. There is a tendency of groups representing different handicapping conditions to contend with each other for improved services.

2. There is difficulty in obtaining accurate figures on the frequency of physical handicaps because the varieties are so numerous.

3. There are biological and environmental hazards causing disease and injury which must be eliminated.

4. There is a need to look at deficiencies in care programs and the quality of living factors for all types of physical handicaps.

5. There is too little money available to treat the physical handicaps in relation to the magnitude of the chronic disease problem in children.

6. There is a need to further emphasize the role of a comprehensive rehabilitation program to maximize independent function, educational achievement, job opportunity, and social acceptance as the right of *all* handicapped persons.

TREATMENT AND HABILITATION CHALLENGES IN MENTAL RETARDATION

Introduction

The term "mental retardation" refers to impairment in intellectual ability and socioadaptive behavior. It is both a symptom of an underlying developmental disorder and an assessment of an individual's potential ability to learn. Thus, the retarded individual learns relatively slowly and his capacity to understand and adapt to social-vocational challenges will be impaired.

Unfortunately, many of the earlier definitions of mental retardation were couched in extremely negative terms which not only set the mentally retarded apart from other members of society, but also conveyed to many people visions of "sub-human" status, seriously restricted ability to develop and learn, and prolonged dependency. All of which was used as justification for not providing services and custodial care and/or overprotection. Thus, negative "self-fulfilling prophecies" were generated which have operated against successfully maximizing retarded persons' levels of functioning. For example, once a severely retarded individual has been labeled as "custodial," living and learning environments are likely to be structured to reflect that label, thereby excluding his progress to a more advanced level of functioning. Although the process of categorization and classification is basic to clinical transactions, labels frequently have been used to exclude retardates from benefits and services which are available to non-retarded persons.

Mental retardation presents a complex set of needs and problems that complicate rehabilitation efforts and family adjustment. Retardation is a major health, educational and social challenge since it represents the most frequent handicap of childhood.

Historical Overview

In this country the beginnings of enlightened treatment programs in mental retardation revolved around the humanitarian efforts of Drs. Edouard Seguin and Samuel G. Howe in the mid-nineteenth century. They were active in assisting the States in establishing schools and residential centers. However, the effectiveness of their efforts was blunted by the basically rural population distribution at that time, the dearth of training centers for producing a large cadre of well trained personnel, and the lack of an advocacy movement to spur the development of extensive service delivery systems.

In the latter portion of the nineteenth century, several factors led to a tragic interlude for the retarded which was to persist until about 1950. These included the rapid acceptance of Binet's test of intelligence as the "only needed" assessment to label one as retarded, over-reliance on brain pathology as the major cause of retardation, and a number of pseudo-scientific "genetic" family studies that presented the retarded as dangerous social misfits. As a result, the previous vibrant beginnings of effective treatment endeavors gave way to a half-century of building huge institutions which placed a premium on low budgets, bench-sitting, and protecting society from its "deviant" retarded members. Overcrowded and understaffed, the institutions became human warehouses—a far cry from earlier concepts about and focus on humane treatment.

Current national interest in the mentally retarded can be traced to the establishment of the National Association for Retarded Citizens (NARC) in 1950 as a citizen advocacy group; and the creation of President John F. Kennedy's Panel on Mental Retardation and the subsequent federal mandate in 1963. For example, NARC has been a pioneer in initiating educational, vocational, and residential models and in encouraging local, state and federal governments to accept these models as part of their services to all retarded citizens. NARC has recently turned its

attention to actively litigating on behalf of the mentally retarded.

The recently completed report of the President's Committee on Mental Retardation, entitled "*Mental Retardation: Century of Decision,*" clearly enumerates what must be accomplished during the remaining years of this century to bring equal rights in treatment, rehabilitation, and other concerns for the retarded.

Vistas in Treatment

Diagnosis—The American Association on Mental Deficiency has established a diagnostic standard which organizes the more than 350 causes of mental retardation into eight distinct groupings on the basis of the known (or suspected) causative factors and associated clinical manifestations. Different levels of mental retardation are manifested at different chronological ages and tend to translate into three types of diagnostic approaches to identify the mentally retarded:

1. Multidisciplinary diagnostic team assessment usually confirms the diagnosis of profound, severe, or moderate mental retardation in infancy and the preschool years.
2. Performance on achievement tests and general under-achievement usually are the cardinal signs which prompt the identification and subsequent diagnostic evaluation of the mildly retarded.
3. At all chronological ages the recognition of some degree of social maladaptability and a vocational inadequacy becomes the major reason for diagnostic referral.

In 1976 President's Committee on Mental Retardation noted that 89 percent of all mentally retarded persons are mildly retarded, 6 percent are moderately retarded, 3.5 percent are severely retarded, and 1.5 percent are profoundly retarded.

The mildly retarded are almost always capable of learning some academic school subjects and to do productive work. As adults they can live independently and become self-supporting if they have received appropriate services during childhood, adolescence, and early adulthood.

Moderately retarded persons can almost always learn to care for themselves. They can profit in varying degrees from classroom instruction, and be trained for repetitive vocational tasks. With stimulation and training from early childhood, most are able to become partially self-supporting and are able to live in the community with some degree of supervision.

Severely retarded persons generally require specialized services at all stages of their lives. They are usually capable of learning to care for themselves; and some of them can become marginally productive adults in sheltered work settings. Recent studies, both in America and abroad, certainly demonstrate that the severely retarded are capable of performing many tasks which were previously thought to be beyond their capabilities.

The profoundly retarded nearly always require major inputs of medical attention and/or supervision in order to remediate medical disabilities and maintain life. Many can be taught some degree of self-care skills, such as feeding and dressing.

In spite of the recent giant strides in diagnostic evaluation, expansion of the federally funded Early and Periodic Screening Diagnosis and Treatment Program is desperately needed. First initiated in 1967, this program gave over 3½ million children their first screening evaluation by June 1975. The impact of early diagnosis and accompanying prescriptive-treatment approaches hold great promise for all handicapped children.

Treatment The hopelessness regarding the treatment of mental retardation which prevailed 20 years ago is no longer with us. Indeed, today we speak of prevention for some, cure for a few, and treatment and habilitation for *all* of our retarded citizens. Effective amelioration of mental retardation is predicated on accepting retarded persons as entitled to the same legal rights and privileges as other citizens. Continued infringement on these rights has led to major legal confrontations during the last decade. The courts have upheld, in a number of benchmark class action suits, retarded citizens' legal rights to public education, treatment, compensation, freedom from harm, and fair classification assessments. Court mandates have ushered in a new era of accountability for professionals and public agencies. Legal decisions have also required that retarded citizens (and parents) be given the opportunity to actively participate in the development and implementation of treatment-habilitation plans.

A major component of the modern approach to amelioration of mental retardation is the principle of normalization, defined as making available to the mentally retarded individuals the patterns and conditions of everyday life which are as close as possible to those of the mainstream of society. Normalization implies integration of the retarded into our society, preferably within his family;

specialization of services in keeping with individual needs; dispersal of services so that large groups of the retarded are not congregated, to the detriment of themselves and others; and continuity of services insuring that changing individual needs are met by appropriate services.

The normalization principle has major consequences for the treatment-habilitation of the mentally retarded. The prediction of the President's Committee on Mental Retardation report that the large public institutions for the retarded will either be gone or drastically altered is inescapable if normalization is to become a reality. The outmoded system of services for its retarded citizens is slowly being supplanted by community-based comprehensive services. These programs are designed to provide the 10 to 12 specialized services—integrated into the mainstream of our society and with a focus on continuity of service needs—which may be needed by a retarded citizen during his lifetime. Specialized services such as infant nurseries, preschool programs, crisis assistance units, vocational centers, and alternative residential living arrangements are utilized to supplement generic services such as diagnostic services, special education, and mental health services.

Research advances must be accompanied by an equally vigorous commitment to narrowing the gap between scientific discovery and clinical practice, including reduction in the delay of new applications while protecting consumers from premature application of new procedures and technology. It is estimated that a 50% reduction in the incidence of mental retardation could be realized if current medical knowledge were fully implemented. The effective and efficient delivery of services to the retarded is a complex issue, however, which will require development and evaluation of new approaches. Meeting the needs of a retarded person involves much more than the delivery of medical services; it is a life-long process requiring broad and continuing community-based services delivered by a wide spectrum of professionals.

Problems Related to the Treatment and Habilitation of the Mentally Retarded

Mental Retardation

1. Research advances in mental retardation must be accompanied by a vigorous commitment to narrowing the gap between scientific discovery and clinical practice.
2. Community-based comprehensive programs, including follow-up, need to be a continuing goal for the mentally retarded.
3. Normalization, as a principle, needs continued and expanding application.
4. Legal rights need to be known and efforts must be made to prevent discrimination.
5. Early and Periodic Screening Diagnosis and Treatment Programs must be expanded.

MENTAL ILLNESS

An estimated 20 million people in the United States are suffering from some form of mental or emotional illness, ranging from mild to severe, that needs psychiatric treatment.[4] Mental illness and other personality disorders are usually significant factors in criminal behavior, delinquency, suicide, alcoholism, narcotic addiction, and divorce. About 9 million people in the United States are alcoholics and alcohol abusers.[5] An estimated 24,440 people committed suicide in 1973.[6] Suicide is now the 11th leading cause of death in the United States. It is estimated there are eight suicide attempts for every suicide committed. As of January, 1976, it is estimated there are 500,000 heroin addicts in the United States.[7]

Anti-social conduct, labeled crime and delinquency, covers a wide range of behavior from truancy and petty larceny to multiple homicide and political assassination. Public expenditures for police, courts, and correction officers are estimated at more than 4 billion dollars annually. The emotional and psychological costs of crime defy measurement in monetary terms, but they affect in numerous ways the lives of countless innocent people.

Following the advent of the tranquilizing drugs in 1955, later the anti-depressants, and more recently lithium, the number of patients confined to state and county medical institutions was reduced from 588,000 in 1955 to 215,573 in 1974.[8] The 1963 forecast of a 50% reduction in state mental hospital populations within 10 years has been achieved. It is anticipated that by 1980, if the rate of decline is to be maintained, there will probably be a two-thirds reduction in the hospitalized mentally ill due to the research which has resulted in new drugs.

Types of Treatment Approaches[9]

A variety of different methods and techniques have been developed to treat and ameliorate mental disorder in its diverse forms and intensity. Some have been practiced for decades, others in the last 10 years.

Psychosocial Approaches—The various psychotherapies which can be grouped under "psychosocial treatment" are premised on the belief that thought, mood and behavior can be influenced by verbal and symbolic interactions between a therapist skilled in such techniques and the disturbed person. One important fact regarding the efficacy of such psychotherapy is particularly relevant to planners of public mental health programs. Patients who benefit most from psychotherapy are usually reasonably well educated, have achieved some social success, are reflective, and are able to experience and express emotion. The question of whether this is related to the therapist and his/her training or to the patient must be answered.

Behavior Therapy—The philosophy and techniques of behavior therapy grew out of research on classical and operant conditioning. Rather than attacking the roots or the causes of mental disorders, the behavioral therapist attempts to alter the visible signs of the disturbance or dysfunction by systematically manipulating the conditions which are believed to produce or reinforce the undesirable behavior.

This form of therapy has been successful in institutions to alter the behavior of some psychotic adults and a small percentage of autistic children. It has been especially useful in reducing self-destructive behavior such as head-banging, self-laceration, and refusal to eat. However, there are increasing indications that some behaviorally instituted changes do not generalize from institutions to outside community living arrangements.

With regard to addictive behavior such as drug use, alcoholism, and smoking, behavior therapy is still not perfected. With the more "abstract" problems usually treated by psychotherapy, behavior therapy is rarely used unless specific behavior problems are present.

Somatic therapy assumes that behavior can be influenced therapeutically by nonpsychological methods such as drugs, shock, and surgery. The major instruments of somatic therapy are the psychotropic or psychoactive drugs. With the perfection of these drugs over the past two decades, it is now possible to stabilize the condition of many schizophrenic, manic-depressive and other seriously disturbed persons; and, thereby, to eliminate the need for prolonged institutionalization in many cases.

Although psychotropic or chemotherapeutic drugs do not "cure" mental illness, they do make it possible to reduce or eliminate the acute episodes of psychotic or disturbed behavior, and, thus, make it possible for many individuals to reside in half-way houses, foster homes, and their own homes.

Another form of somatic therapy is electroconvulsive therapy (ECT) or shock treatment. Although the use of ECT has been reduced markedly in the past decade, some therapists maintain that it is the most effective and rapid-acting treatment for the relief of the symptoms of severe depression and other disorders.

Psychosurgery, or the removal or destruction of brain tissue, was used in the past to alter mood, thought and behavior. The technique is rarely used today, except in the presence of organic problems which can be corrected by surgery.

Other Techniques—Within the past decade there has been a dramatic increase in the use of new treatment techniques, including megavitamin therapy, "biofeedback," transcendental meditation, acupuncture, encounter groups, and other techniques associated with the "human growth" movement or primal therapy. Research is required to determine the effectiveness of such techniques.

Special Concerns

Within that portion of the population who may need mental health treatment, there are some groups whose specific problems require special emphasis, namely children, the elderly, minority persons and the severely mentally disabled.

Children—During the past decade, the inadequacy of mental health treatment services for children has been continually brought to the public's attention. Although services have been expanded during this period, they are still inadequate. There is a continuing need for more day treatment centers, residential programs, special education services, and specialized foster homes.

Elderly—A significant portion of persons residing in state institutions for the mentally ill are over 65 years of age. Many have been there long periods; others are admitted in later life as a result of senility and other disturbances associated with

old age. Many of these individuals are not necessarily mentally ill but are dependent persons with no where else to go. Other facilities are obviously needed for these persons.

C. *Minority Persons*—The difficulty of determining the appropriateness and efficacy of treatment for this group is great. Prejudice and difficulties in communication play a role; so, often, do poverty, malnutrition, and unemployment. In poor communities the first identification is usually made by the police. Symptoms are sometimes called neurotic in whites and psychotic or psychopathic in blacks. Third-generation white patients are accepted for psychotherapy significantly more often than people of the same socioeconomic class who are blacks or Mexican Americans.[4]

Severely Mentally Disabled—The severely or chronically mentally disabled person has treatment needs which may vary in intensity and kind from those of the mildly disabled person. In addition to intensive psychiatric attention, such persons may also require transitional services to help them readjust to community living; specialized living arrangements to meet their needs; medication supervision; and case management to assure that they receive both the required therapeutic and support services.

Trends

A. Reduction in Involuntary Treatment

Unlike persons with other disabilities, with the possible exception of tuberculosis and leprosy, the mentally ill have traditionally been subject to involuntary treatment and incarceration. During the 1960's, in California alone, 1,000 persons a month were admitted to that state's mental hospitals against their will.[6] Recently an increasing interest in the civil liberties of such persons has begun to reverse this trend. More and more states are beginning to adopt statutes which require that a mentally ill individual be dangerous or unable to care for himself or herself before (s)he can be involuntarily held.

B. Involvement of Patients in the Treatment Process

It is hoped that by involving the patient in the treatment process his or her dignity and self-esteem will be reinforced and individual efficacy will be maintained.[10]

C. Increase in Family Therapy

Twenty years ago interest in the family as a contributor to mental illness and behavior disorders began to rise. Research focused on possible mental illness problems among persons in the patient's immediate family, then on the nature of the relationships among family members, and finally on the patterns of communication within the family. All of this attention has stimulated the development of family therapy programs and an increasing focus on the patient's total environment rather than on his problems and symptoms in isolation.[10]

E. Increased Diversity in Personnel

Whereas the treatment of mental illness was traditionally within the strict purview of the medical profession, in the past several years a variety of other professionals have begun to play a direct role in the amelioration of mental illness. The list of persons who can now be considered mental health professionals includes social workers; psychologists; special education teachers; occupational, art, and recreational therapists; nurses; rehabilitation specialists; and psychiatric technicians. There is also an increasing use of "mental health workers" who are frequently indigenous members of the community, such as in low income areas, who are capable of providing a variety of support services.

The diversity of approaches which each of these groups brings to bear on the problem of mental illness has also encouraged the use of multidisciplinary teams in treatment planning, periodic review, and the provision of treatment services.

Continuity of Treatment Programs

Although a variety of services for the mentally ill currently exist in many communities, there is a need to link these services in a coherent pattern to assure that patients do not "fall between the cracks." Such a continuum will also assist in the ability of the system to respond to the changing needs of the patient as he moves from lower to higher levels of emotional functioning.

Problems Related to the Treatment and Rehabilitation of the Mentally Ill

1. Tremendous numbers of persons are unserved and the result is a high suicide rate, drug addition, crime and other social crises.
2. Children's services are especially inadequate, including day service and residential services.

3. Lack of proper facilities for the elderly force them to reside in facilities which are inappropriate to their mental health.

4. Prejudice and difficulties in communication make it difficult to determine appropriateness and efficiency of treatment for minority and low income persons.

5. A continuum of community services is needed.

DEAFNESS

Approximately 2,000,000 Americans lack sufficient hearing to understand speech.[11] Nearly one of every 10 persons has some degree of hearing loss, and the incidence of hearing loss is increasing in the United States, despite efforts to control it.[12]

Through research and improved pediatric practices, more premature children survive despite a stormy early life. The incidence of hearing problems among premature children is nearly seven times that found in normal full-term deliveries.[12] Hearing loss is generally broken down into two major categories:[13] (1) middle-ear, or conductive, hearing loss and (2) sensorineural hearing loss from perinatal neural damage or developmental defects, the aging process and vascular degenerative changes, the effects of some drugs, prolonged exposure to excessive noise, and certain types of genetic disorders.

One of the greatest dividends in medical research in deafness is in micro surgery which has been developed to restore hearing to individuals who suffer from middle ear (conductive) deficiencies and mastoid infections. Acute mastoid disease has been dramatically reduced and almost eliminated by the use of antibiotics and surgery. Other advances have been made through regional temporal bone banks and other techniques.

Experience has shown that broad public health programs are highly beneficial when they introduce early measures to control or cure hearing losses. Prenatal clinics continue their attempt to reduce the incidence of prenatal infection. At birth, there is better control of the problems of erythroblastosis and oxygen deprivation, and improved obstetrical techniques help prevent children from receiving injuries or infections that will lead to hearing handicaps.

Problems Related to the Prevention and Treatment of Deafness

1. Obstetrical techniques are needed in prenatal clinics to prevent problems leading to hearing handicaps.

2. Financial aid is necessary for those with limited income needing surgery and/or hearing aid devices.

VISION—EYE CARE AND TREATMENT

Extent of the Problem

An estimated 9,596,000 people in the United States have some degree of visual impairment.[14] Of these 1,306,000 have such severe visual impairment that they are unable to read ordinary newsprint with either eye, even with glasses. In addition, 94,000,000 people wear glasses or contact lenses to improve their vision.

At least 475,000 people in the United States are legally blind. An estimated 44,350 people become blind each year.[15]

Main Causes of Blindness

The main causes of blindness in the United STates are retinal disease, glaucoma, and cataracts.[16]

Retinal diseases, conditions affecting the retina which is the the light-sensitive tissue at the back of the eye, account for a minimum of 76,500 of the blind population in the United States. This does not include the thousands of individuals who suffer disability from these diseases but are not blind.

Glaucoma affects 797,000 persons. Of these 470,000 are 65 years of age and older; 268,000 are 45 to 64 years of age; and 52,000 are 17 to 44 years of age. In glaucoma visual function is lost because of damage to the optic nerve associated with an increase in intraocular pressure. Vision loss from glaucoma cannot be restored.

Cataracts are manifested by a cloudiness of the lens of the eye that interferes with vision. Approximately 3,013,000 individuals suffer from cataracts; and more than two-thirds of these persons are 65 years of age and older. More than 40,000 people are blind because of cataracts, and more than 4,400,000 lost their sight in 1972 because of cataracts. Cataract extraction is one of the most successful operations performed today,

with 90% to 95% of the patients having their vision restored.

Rehabilitation Engineering

Rehabilitation Engineering Centers have been established by the Department of Health, Education and Welfare (HEW) to provide total rehabilitation engineering care and treatment of patients. Research and development, evaluation, and educational activities are part of the eight centers which have already been established.

The two federal agencies (HEW and VA) primarily responsible for health care delivery have already made some progress, not only in applying available resources efficiently to research and development and education, but also in improving the system for delivery of services to patients at VA hospitals and clients of state agencies for vocational rehabilitation.

Included in rehabilitation engineering are fields such as prosthetics and orthotics, neuromuscular, sensory, and skeletal implants, sensory aids, communication aids, vocational aids, mobility aids including vehicle systems for the handicapped, systems to cope with environmental barriers, including some aspects of architecture, physiological monitors, and all forms of technical aids from the simplest crutch to the most complex computer which enhance the quality of life for the handicapped.

Immediately following World War II, achievements resulted, particularly in prosthetics, from the impetus provided by the clearly expressed needs of the returning disabled veterans. The VA, with the Department of Defense and the National Academy of Science, organized a research program which improved the state of the art in prosthetics over the years immediately following World War II. The VA also launched an educational program to teach developments coming from the laboratories to practitioners throughout the country. Later the Office of Vocational Rehabilitation of HEW became involved in funding research and development, and, most particularly, the educational programs organized at several universities in concern with the VA. To coordinate this program the VA and HEW engaged the services of the National Academy of Science Committee on Prosthetics Research and Development, which provided guidance to the funding agencies, particularly in defining clinical needs and then monitoring research, development, evaluation, and educational efforts.

In the 1960's HEW and the VA first expanded the scope of their efforts to include orthotics (the making of braces) and then to the other applications of technology. They have coordinated their efforts with other federal agencies such as NASA, the Department of Defense, the Department of Transportation and many universities. A major problem exists in providing funding for established educational centers and universities to promote preparatory and post-graduate educational programs for the professionals in this field. There is also a serious lag between the development of technological advances in the laboratory and their introduction to the clinical management of patients by these front line professionals.

Dentistry for the Handicapped

Dental disease represents a major health problem experienced by many, if not all, handicapped citizens. Many studies have reported on the incidence and devastating effects of oral pathology among individuals with mental and/or physical disabilities. Handicapped citizens as a group find dental treatment difficult to locate and purchase, as a great majority of dental offices in the past have been inaccessible because of architectural barriers. Although the delivery of dental health services to handicapped children is insufficient, it is further diminished for handicapped adults. The lack of education both of dentists and parents is related to the unfortunate level of oral disease experienced by handicapped individuals.

The approximately 4,000 dentists who graduate from dental schools each year are not sufficiently trained to provide proper dental treatment to people with various handicapping conditions. An innovative development is noted which is designed to ameliorate this apparent deficit in manpower. The Robert Wood Johnson Foundation has awarded 4.7 million dollars over a three-year period to 10 dental schools. The purpose of this award is for curriculum development and training of dental students in the care of handicapped patients.

The problem of inadequate dental care for the handicapped is compounded by the absence in most communities of a policy regarding dental care for the handicapped and a multi-professional group to implement such a policy. Inadequacy of communications between organized dentistry and groups working on behalf of the handicapped not

only interferes with the development of a plan which is systematic and comprehensive but also hinders the dissemination of information regarding preventive dentistry to handicapped individuals, their parents, and teachers en masse. The consequence is crisis oriented care for a large segment of the handicapped population. Access to dental health services is limited in any health care delivery system for the disadvantaged. In addition to the economic factors that condition this lack of availability, cultural factors and knowledge of how to use personal health services and other welfare services are all relevant in this context. Among the economically disadvantaged, a lower level of use of primary health services is perhaps most clearly evidenced in dental care, possibly the most neglected aspect of the health of the poor.

For those persons whose teeth have been extracted and who do not have dentures, the hardships they suffer in terms of their appearance are often coupled with alterations in diet that can potentially contribute to obesity and related metabolic disorders. Additionally, individuals handicapped by speech pathology often cannot articulate their need for dental care and the presence of oral pathology can create needless speech difficulties.

Dentistry for the Handicapped Problems

1. Handicapped citizens find dental treatment difficult to locate and purchase.
2. Lack of proper education of dentists about handicapping conditions and dental treatment for people with various handicapping conditions.
3. Inadequacy of communications between organized dentistry and groups working on behalf of the handicapped.
4. Cultural factors and knowledge of how to use personal health services limit the availability for the disadvantaged.
5. Individuals with speech problems cannot articulate their need for dental care.

Conclusion

Although the rehabilitation movement in the United States is one of the greatest examples of humanitarian accomplishment in our time it nonetheless remains unfinished business. Children are still found in their homes undiagnosed and untreated, amputees still walk the streets without prosthesis, discharged patients still sit in their homes unable to get out, lacking transportation, funds, jobs and accessible housing.

The treatment aspect of rehabilitation if limited to post acute care and some single discipline form of chronic care can be paid to be available for the physically handicapped. Early care and universal, comprehensive rehabilitation is not.

Strides in programming for the retarded have been giant sized but the battle of adequate treatment for the vast numbers in the population and the battle of public attitudes remain.

The third major category, mentally ill, is a common problem as seen by daily statistics of crime, drug addition and suicide yet the resistance to treatment, cost of treatment and accessibility of services does not reflect the needs.

Pride in advances in treatment as a part of rehabilitation must not block the vision of providers, advocates and consumers to the still glaring need for progress.

1. Howard A. Rusk, M.D., Rehabilitation, Excerpta Medica, Section 1X, Surgery, Vol. 10, December issue, 1956.
2. National Health: Vital and Health Statistics. Data from the National Health Survey, Series 10–No. 112. National Center for Health Statistics, 1974.
3. Areawide Planning of Facilities for Rehabilitation Services, U.S. Department of Health, Education and Welfare, Public Health Service, Washington, D.C., Public Health Service Publication No. 930–B–2, April 1963.
4. Data from National Association for Mental Health, Arlington, Va., 22209.
5. First Special Report to the U.S. Congress on Alcohol and Health from the Secretary of Health, Education and Welfare, December, 1971.
6. National Center for Health Statistics, U.S. Public Health Service, Rockville, Maryland.
7. Statistical Abstract of the U.S., 93rd ed., U.S. Bureau of Census, Washington, D.C., 1972
8. Statistical Note 114, Survey and Reports Section, National Institute of Mental Health, Rockville, Md., April, 1975.
9. National Institute of Mental Health, The Impact of Research and Applied Technology on the Diagnosis and Treatment of Mental Illness, (excerpted from the Summary Report of the Research Task Force of the National Institute of Mental Health, G.P.O., DHEW Publication No. (Adm.) 750237), 1975. The discussion is of the treatment approaches based on information in the above document.

10. Don D. Jackson, Family Interaction, Family Homeostasis; and Some Implications for Conjoint Family Therapy, Science and Psychoanalysis, II, pp. 112–141, 1959.
11. Preliminary estimate prepared for the government by the Deafness Research and Training Center, New York University, New York, N.Y.
12. Hearing Loss—Hope Through Research, publication of the National Institute of Neurological and Communicative Disorders and Stroke, Bethesda, Md., 20014.
13. John E. Bordley, M.D., Andelot Professor, Emeritus, Otolaryngology, John Hopkins University, School of Medicine, Baltimore, Md., 21205. Personal communication.
14. National Center for Health Statistics, unpublished data based on household interviews of the 1971 civilian, non-institutional population of 202,360,000, 1971.
15. Elizabeth Macfarlane Hatfield, M.P.H., Estimates of Blindness in the United States, The Sight-Saving Review 32, No. 2, Summer of 1973.
16. Application of the 1970 rate of legal blindness in the Model Reporting Area (14 states) to December 1972 estimate U.S. resident population of 208,966,000. (Series P–25, No. 495, January, 1973, U. S. Bureau of the Census.
17. National Citizens Advisory Committee on Vocational Rehabilitation, A Report to the Secretary of Health, Education and Welfare by the National Citizens Advisory Committee on Vocational Rehabilitation, Page 7, Washington, D.C., June 26, 1968.

ATTITUDES OF THE GENERAL PUBLIC TOWARD HANDICAPPED INDIVIDUALS

Awareness Paper Prepared By

Harold E. Yuker, Ph.D.
Hofstra University
Hempstead, New York

ACKNOWLEDGMENT

The White House Conference on Handicapped Individuals wishes to thank, for his review of this paper:

Dr. Robert E. Kleck
Department of Psychology
Dartmouth College
Hanover, New Hampshire

TABLE OF CONTENTS

	Page
Introduction	93
The Nature of Attitudes	93
Attitudes and Behavior	93
Situational Influences on Attitudes	94
Attitudes Toward Handicapped People in General	94
Relationship to Other Attitudes	94
Correlates of Attitudes Toward Handicapped Persons	95
Attitudes Toward Specific Handicaps	95
Physical Handicaps	95
Mental Illness	96
Mental Retardation	96
The Disability Hierarchies	97
Effects of Education and Information on Attitudes	97
The Message and the Medium	98
The Source	98
Recipient Characteristics	99
Recipient Behavior	99
The Effects of Contact	100
Contact Variables	100
Information and Contact	101
Attitudes of Specific Groups	101
Relatives	101
Professional Personnel and Staff	101
Employers	102
Effective Attitude Change Procedures: Direct Techniques	102
Information Campaigns	102
Role Playing	103
Counterattitudinal Advocacy	103
Public Commitment	103
Indirect Techniques	103
Integration	103
Changing Handicapped People	104
Changing the Environment	104
Some Needed Research	104
Bibliography	105

INTRODUCTION

A front page article in the *Wall Street Journal* on January 27, 1976 pointed out that the major barriers to the employment of eight million disabled people are attitudinal. While attitudes have changed somewhat in the last several years, there is still a long way to go. We need to understand attitudes, their sources, and their dynamics in order to make progress toward the goal of acceptance of handicapped persons as full and equal partners in our society.

The Nature of Attitudes

Attitudes may be thought of as positive or negative emotional reactions to an object, reactions that are accompanied by specific beliefs and that tend to impel the individual to behave in specific ways toward the object of the attitude. This definition indicates that attitudes have three components: a belief component, an emotional component, and an action component.

Consider attitudes toward handicapped persons. Most people will have acquired a set of beliefs based on things they have heard and upon specific experiences they have had with persons who are disabled. One person might believe that all handicapped persons are ugly, stupid, strange, inferior, and frightening. Someone else might believe that most persons with handicaps are similar to persons without handicaps. A third might believe that many disabled people are superior as a result of the difficult lives they have led and the problems they have learned to surmount. Almost any beliefs are theoretically possible. Some persons may have many specific ideas about handicapped people, others might have only a few general ideas, and some might have no beliefs at all.

Positive, or complimentary beliefs are accompanied by liking and positive feelings. Uncomplimentary and negative beliefs are accompanied by dislike and negative feelings. These are aspects of the emotional component of attitudes.

Finally, attitudes represent a tendency to act. If the beliefs and feelings are positive, there will be a tendency to move toward the object of the attitude, and to say and do nice things. If the beliefs and feelings are negative there will be a tendency to avoid the object, or to say or do negative things. If the beliefs and feelings are ambivalent, the person's actions will vacillate, sometimes they will be positive, other times they will be negative.

Beliefs, feelings, and action tendencies are learned. They result from a combination of what an individual learns from people who are important to him (such as parents, friends, and teachers), and what he learns from his own experiences. A person who has few contacts with handicapped people will probably adopt the attitudes of the people he knows, likes, and respects. If a person has interacted with disabled people, the reactions to these interactions will modify the beliefs stemming from the teachings of significant others. Some kinds of interaction lead to positive beliefs, other kinds to negative beliefs.

Attitudes and Behavior

Behavior does not always correspond to beliefs and feelings. Often there is a discrepancy between what people think, what they say, and what they do. What people do, the action component of an attitude, including its verbal expression, is influenced by social environmental factors that are present when the attitude is expressed or the action taken.

Consider attitudes toward employment of handicapped people. Suppose an employer has a discussion with someone representing the Governor's Committee on the Employment of the Handicapped (GCEH). During the discussion the employer agrees with the GCEH representative that "hiring the handicapped is good business," and he agrees to hire several handicapped persons. Later, he calls in his personnel manager and tells her to hire persons who are handicapped. She first agrees, but then gives many of the typical arguments against such a course of action. Since many of the anti-hiring arguments seem reasonable (just as the pro-hiring arguments seemed reasonable in the earlier situation), the well-intentioned employer now agrees with his personnel manager. No attempt is made to hire handicapped individuals. In a third, later situation, the employer may again express positive attitudes and give excuses for not having hired disabled people.

This lack of correspondence between words and actions has a very important implication. If we want to change people's behavior, the action component of attitudes, rather than just the emotional and belief components, we have to

use techniques that are effective in changing behavior.

Situational Influences on Attitudes

Attitudes expressed by other individuals who are present at a given time are not the only situational influences on a person's behavior. The standards or values that are dominant within a given society, or within a subgroup of that society, are also influential. If a society considers handicapped people valuable citizens and states that they are entitled to equal treatment, most of the members of that society will express positive attitudes and show positive behavior. But if a society shows either negative attitudes or lack of concern and interest in handicapped citizens, most people will express negative attitudes that are consistent with the negative group norms.

Studies of attitudes toward mentally ill people have shown that attitudes toward emotionally disturbed persons vary from one community to another. The variations are influenced by the availability of mental health professionals and treatment facilities within the community. Where clinics and therapists are available, a market for services is created, treatment becomes more common, and attitudes tend to be more positive. In such situations (e.g. in situations where patients at mental hospitals work in a community), mentally ill persons are perceived as "normal" and they are valued more positively. On the other hand, attitudes often tend to be negative in communities where there are unemployed former mental patients who wander around all day with nothing to do.

Thus, in order to improve attitudes toward disabled people, first we need to examine the attitudes prevalent in the nation, the state, and the community. Then we must attempt to establish values and norms that reflect positive rather than negative attitudes toward handicapped persons.

ATTITUDES TOWARD HANDICAPPED PEOPLE IN GENERAL

Since World War II there have been many discussions, analyses, and studies of attitudes toward handicapped people. Although the results of the research were not always consistent, we are able to summarize some of the general findings:

1. Although people make distinctions among types of disabilities, they also are willing to express attitudes toward disabled people in general. Even though individuals differ in the specific groups that they include when they speak of "the handicapped," their attitudes toward people with different handicaps tend to be quite similar.
2. In response to direct questions, more than 50% of the people in the United States express slightly positive attitudes toward disabled people and indicate that they have sympathetic feelings for them. Other people, however, have negative, rejecting attitudes, and a few of them express these attitudes quite openly.
3. Many non-disabled individuals perceive handicapped people as "different" and in some ways inferior to "normal" people. They are uncomfortable in the presence of handicapped people. They "don't know how to behave," which implies that they believe one should behave differently in the presence of a person with a disability.
4. Despite the positive attitudes that are expressed in public, handicapped persons are often discriminated against. Many people favor segregation rather than integration of handicapped individuals. Possibly because of feelings of discomfort, or feelings that they are different, disabled people are often treated as if they were different.
5. Attitudes toward handicapped people often have negative aspects, the strength of which varies from one person to another. One such aspect relates to fears that "this could happen to me." Another relates to the tendency to reject people who are different.
6. Individual differences in attitudes are very large as a result of differences in peoples' knowledge and past experiences.

Relationship to Other Attitudes

Many studies have indicated that attitudes toward one object tend to be related to and influenced by attitudes toward another object, particularly if the two objects are similar in some way. Thus, individuals often have generalized attitudes toward people; some individuals like people and are accepting of them, others do not like most people. Some people tend to distrust, dislike, and reject anyone whom they perceive as being different from themselves in

terms of race, religion, appearance, attitudes, etc.

Several social scientists who have studied attitudes toward handicapped persons have suggested that handicapped people could be considered to be members of a minority group. Many studies have confirmed this view. People who have negative attitudes toward minority groups also have negative attitudes toward disabled people, just as people who have negative attitudes toward persons with one specific type of handicap usually have negative attitudes toward handicapped people in general. Thus the evidence justifies regarding attitudes toward handicapped people as part of a constellation of attitudes towards persons who are physically or psychologically "different."

Although the research results are not always consistent, several other attitudes have been shown to be correlated with attitudes toward disabled persons: 1) People with authoritarian attitudes tend to show more negative attitudes and more rejection of disabled people; 2) People with Machiavellian attitudes (tend to view people as manipulable or exploitable for one's own purposes) tend to have negative attitudes toward disabled persons; and 3) People who have positive attitudes toward themselves have more positive and accepting attitudes toward disabled individuals. Studies of most other attitudes have yielded conflicting results.

Correlates of Attitudes Toward Handicapped Persons

What kinds of people have what kinds of attitudes toward handicapped persons? Age has been one of the factors studied, and the results have been inconclusive. Although some studies indicate an increasing tendency for attitudes to become positive from the time one begins school up to the age of about 60, most studies fail to report this relationship. Consequently the most prudent conclusion would be to attribute any changes that occur to the influence of factors other than age. Becoming older is, unfortunately, not sufficient to guarantee that one will become more accepting.

The sex of the person may also have a relationship to the attitudes held. While many studies have found attitudinal differences between men and women, other studies have not found these differences. However, when differences have been found, women usually have been reported as having more favorable attitudes toward disabled persons than men.

Some studies have reported relationships between attitudes and marital status, social class or socio-economic status, or ethnic group identification; other researchers have reported a lack of relationship. The point of view adopted here is that when such relationships are found, they can be attributed to the effects of major variables such as information and contact, rather than to the effects of demographic factors *per se*.

ATTITUDES TOWARD SPECIFIC HANDICAPS

Grouping attitudes toward all disabled people together is inadequate for some purposes since it tends to obscure important differences. Data indicate that some people have different attitudes toward different disabilities, and some groups, such as employers, consider the differences to be very important.

The three categories that will be discussed are the physically disabled, the mentally ill, and the mentally retarded. Most studies deal with only one of these areas and do not even refer to the others. Each has some good information about measurement techniques, effective methods of changing attitudes, etc. But cross fertilization of ideas is lacking.

This overspecialization is also apparent in the lack of interest in studying the similarity of attitudes toward disabled persons and other minority groups, particularly ethnic minorities. While there are important differences between attitudes based on racial factors and attitudes based on physical and mental characteristics, there also are important similarities. Few studies have discussed the similarities. Exceptions are the works of Wright (1960) and Yuker, Block and Young (1966) who emphasize the minority status of disabled persons.

Physical Handicaps

Attitudes depend in large part on the amount and type of *contact* that people have with individuals who have a particular disability. They depend to a lesser extent on the *information* that people have about a disability. In recent years the increasing integration of some types of handicapped individuals into the "normal" everyday life of the nation has resulted in an increase in positive attitudes toward

disabled persons. Changes also have been fostered by the educational and informational campaigns carried on by the Federal government and by the national organizations concerned with specific types of handicaps.

We can briefly summarize some of the common attitudes toward disability groups:

1. The attitudes toward people with sensory handicaps such as blindness and deafness are favorable compared to other physical disabilities. Their functional limitations are taken for granted. Although most individuals fear sensory loss, particularly blindness, there is little feeling of aversion toward people with this handicap. In fact, many people are impressed by the achievements of people with sensory handicaps.

2. Attitudes toward people with loss of one or two extremities, or loss of function in one or two extremities, tend not to be negative. In most cases, people believe that the loss of function can be compensated by the use of an appropriate prosthesis. Individuals in these categories are usually considered to be both competent and comparatively self-sufficient.

3. Attitudes toward people with facial or body deformities usually are negative, even though these persons may have all of their functional capacities. Most societies put a premium on "normal" appearances and "normal" ways of doing things. Ugly people tend to be rejected and people with deformities are often considered ugly. Examples are, persons with facial disorders from burns and disorders of body size such as people of small stature.

4. Finally, people who exhibit uncoordinated and unpredictable behavior, such as some persons with cerebral palsy, often experience negative attitudes and a high degree of rejection. Usually there is ignorance about these disabilities and their effects. People are uncomfortable relating to individuals with these handicaps and assume that they are helpless and nothing can be done either by them or for them.

Mental Illness

A mentally ill person is often defined as someone who has been treated or hospitalized for a psychological disturbance. Mental illness is unlike most of the other types of disability being discussed in the extent to which it is recognizable. The appearance and/or behavior of most disabled people serves to make them clearly distinguishable. This is not true of most persons who are mentally ill. Their behavior is "normal" much of the time. And even when it is abnormal it is often mislabled as "eccentric" or due to the effects of alcohol or drugs. Only in recent years have people begun to recognize the symptoms of mental illness.

Early studies indicated that people who were labeled as being mentally ill, or had spent time in a mental hospital were feared, stigmatized, and avoided. People did not accept the present medical model in which mental illness is viewed as an entity to be diagnosed and treated in the same manner as other physical ailments. They tended to be outspoken about the discomfort and anxiety that they felt when interacting with a person who was considered mentally ill. Compared to "normal" people, mentally ill persons were sometimes considered worthless, dangerous, and unpredictable.

In recent years there have been changes in these attitudes. Data indicate that people are more informed about mental illness today. They are aware that they should accept the medical model and view mental illness as similar to any other transitory illness. But despite the awareness, emotionally this view does not always prevail. Many people are still frightened and/or repelled by the idea of interacting with a mental patient, or even a former mental patient. They exhibit negative and rejecting behavior.

Mental Retardation

It is difficult to generalize about mentally retarded individuals because of the great differences in behavior of a severely retarded individual and one who is mildly retarded. Severely retarded persons evoke very negative attitudes and experience extreme rejection, while persons who are mildly retarded are often liked and partially accepted. In some ways mentally retarded persons are much more similar to persons who are physically disabled than to persons who are mentally ill. Many are quite readily identifiable by their behavior or their speech, and sometimes by their physical characteristics. On the other hand, they may be viewed as similar to mentally ill persons since their behavior may be perceived as unpredictable and dangerous.

Attitudes toward mentally retarded individuals, like attitudes toward other handicapped

groups, are dependent upon contact and information. Since most people have either no contact or very limited contact with mentally retarded persons and have been exposed to little information regarding them, they tend to be both fearful and rejecting of this group. Studies have shown that severe retardation is among the least acceptable of all handicaps. However, these attitudes do not exist among people who have interacted with retarded persons in ways that illustrated the abilities of the person, rather than focusing on the individual's disability.

The Disability Hierarchies

Several studies have been performed in which people were asked to rank several different handicaps in terms of their comparative acceptability under various sets of conditions. It has been shown that the labels used can make a lot of difference (e.g. "crippled" versus "amputee" and "emotionally disturbed" versus "mentally ill"). The rank order obtained also depended on who was doing the ratings, and what situations were being considered.

Discussions of the underlying reasons for the disability hierarchy have focused on several important factors:

1. The social acceptability of the handicap appears to be related to the visibility of the handicap, the extent to which it involves a disfigurement, and the extent to which social interaction involves feelings of discomfort or inability to predict the behavior of the handicapped person. In this hierarchy, blindness is more acceptable than deafness, and cerebral palsy and disfiguring handicaps are least acceptable.

2. The extent of the handicap, the degree to which it interferes with locomotion, communication, thinking, and relating to people, or all of these, are important factors. In this hierarchy disfiguring handicaps are at the top of the list and deafness is more acceptable than blindness.

3. Another factor is, "How would I feel if this happened to me?" Most people greatly fear becoming blind, even though it is socially acceptable and less handicapping than some disabilities. But there are great individual differences. Some people view the loss of a finger as a major handicap while others view the loss of an entire limb as a minor inconvenience that can be adjusted to.

4. To what extent is the individual responsible for the disability? Data indicate that many people are more rejecting of disabilities that are considered to be the fault of the disabled individual than they are of disabilities resulting from external causes. For example, studies have shown high degrees of rejection for alcoholics.

Thus, there are several hierarchies, not just one. If we summarize and combine we are left with five classes: 1) The most acceptable handicaps are those that are comparatively minor such as people who are partially seeing, speech handicapped, have heart disease or an ulcer, are hard of hearing, etc.; 2) Next most acceptable are people who have suffered the loss of one or more extremities such as persons who are paralyzed or amputees, etc.; 3) The middle category consists of people with the complete loss of a major sense such as vision or hearing; 4) People who are mentally ill tend not to be accepted and are usually rejected; 5) People with acute and chronic brain injuries such as epilepsy, cerebral palsy, or mental retardation are at the bottom of the list of acceptability. This summary list is intended only as an overview and should be interpreted with caution. Nevertheless, it is important because it relates to attitude change. Attitudes toward groups near the top of the list are easier to change than attitudes toward groups near the bottom of the list.

There are also wide ranges of acceptability to degrees of disability within most categories. For example, mental retardation and cerebral palsy can be either mild or severe. Most persons react differently to a person who seems to be severely disabled than they do to a person with a mild disability or a person who appears to be adequately coping.

EFFECTS OF EDUCATION AND INFORMATION ON ATTITUDES

Although most people assume that education and information are effective ways of changing attitudes, most social scientists are skeptical of this view. Data obtained from studies indicate that about 50% of the time increased information results in a positive change in attitude and increased acceptance of handicapped persons. The rest of the time the information appears to

have no effect, although occasionally some people are "turned off" by educational campaigns and become more negative in their attitudes. Information does not have any *automatic* effect on attitudes.

But since information frequently does have an effect, it becomes important to determine the factors that account for the effect. Research has revealed several factors that interact to influence the effect of a communication: 1) the content of the message and the medium through which it is presented; 2) the source of the communication; 3) the characteristics of the person who receives the communication; and 4) the behavior engaged in by the person who receives the communication.

The Message and the Medium

Data obtained pertaining to the comparative effectiveness of alternative messages transmitted through different media lead to the following conclusions:

1. The most effective messages are ones that either provide new information or that provide information that fits in with what a person already knows.
2. Messages that state explicit conclusions are more effective than ones that let the listener draw her or his own conclusions.
3. There is not much difference in the effectiveness of appeals based on emotion and appeals based on reason.
4. Presenting both the positive and negative aspects of the situation is more effective in changing attitudes than is presenting just the positive aspects of the situation, particularly with people who are very intelligent, and with people who initially have negative attitudes.
5. The presentation of information by one person to another, in a situation involving interaction, is more effective than any other technique of communication, including the mass media (newspapers, magazines, radio, television, etc.).
6. A two-step flow of communication is a very effective technique. According to this theory, in the first step information is passed from the media to opinion leaders such as educators, other professional people, community leaders, political leaders, etc. In the second step the opinion leaders pass on their information, often through personal contact, to members of the general public. Thus, it is important to get the attention of the opinion leaders and provide them with information that can be passed on to the members of their constituencies.
7. The spoken word is usually more effective than written material, even though tests indicate that comprehension is greater for reading than for hearing.
8. The mass media has an effect on some people, some of the time. Usually, however, it affects only a small percent of the audience, and the effects tend to be transitory.

The Source

The same message delivered by different people may have different effects. Consider the comparative effect of a discussion aimed at convincing a businessman that "hiring handicapped people is good business." Three different sources, a disabled person seeking a job, a government employee trying to find jobs for disabled workers, and a successful businessman who has hired disabled workers and been very satisfied with their performances, will have varying degrees of success in getting the message across.

Discussions of important source characteristics usually focus on three factors: credibility, attractiveness, and power. A person that is credible, one that can be believed, is more likely to have an effect. Non-credible sources fail to change attitudes. Credibility depends on the expertise and the trustworthiness of the source of the communication. People who are paid for saying something and those who have "an ax to grind" are less credible than those who appear to be disinterested. Credibility also depends on the prestige of the source. Well known people tend to be trusted and listened to. This is why they are frequently asked to do commercials.

Attractive sources are also likely to be listened to. Attractiveness is usually hard to measure since it lies in the eyes of the beholder. In general, however, research indicates that people tend to like, or see as attractive, people who are similar to them in age, occupation, income, interests, etc. Familiarity is another source of attraction. Messages delivered by famous people such as stars of sports and entertainment, are often more effective than

messages delivered by unknown persons. Familiarity, in these situations, usually tends to breed attraction rather than contempt.

Finally, communication effectiveness is increased if the source of the message is powerful. A powerful source is one that is both willing and able to enforce the effectiveness of a message such as an employer who has the power to control some of the behavior of his employees, or a government official who has the power to enforce laws and regulations.

These three variables can help explain the comparative effectiveness of several sources mentioned earlier with respect to the message "to hire handicapped people." The disabled person will have low credibility because he/she has an "ax to grind," medium to low attractiveness since most people perceive disabled persons as different and unfamiliar, and very little power—unless a suit is threatened on the basis of discrimination. The government employee will probably have medium credibility since she will probably be viewed as an expert, but someone being paid to do a job; her attractiveness will depend on specific personal characteristics, and her power will depend on the clout of the agency that she represents. The successful businessman will have high credibility since he gains nothing from the message, is probably very attractive to other businessmen, and may be viewed as powerful even though he cannot force anyone outside his business to hire disabled workers.

Recipient Characteristics

Since it is reasonable to assume that the effect of a communication will depend upon the personal characteristics of the individual who receives the message, many studies have attempted to determine which characteristics are important. The only factors that have consistently been found to be important are those related to the pre-existing attitude structure of a person.

Data lead to several conclusions regarding what kinds of attitudes are comparatively hard to change and what kinds are easy to change:

1. Extreme attitudes are more difficult to change than moderate ones. People with very negative attitudes toward handicapped citizens will be hard to reach, those who are mildly rejecting will be more susceptible to persuasive communications.

2. Attitudes that are based on many beliefs and much information will be very hard to change, even if the "original" information was incorrect. It is much more difficult to counteract negative beliefs than to provide information that will lead to positive beliefs.

3. Attitudes that are part of an interrelated system of consistent beliefs will be difficult to change. For example, a person who has negative attitudes toward all disability groups will be quite hard to change, while a person who doesn't like persons who are mentally retarded, but who is accepting of most other disability groups will be easier to convince.

4. Attitudes that are similar to those held by the members of a person's reference (i.e. peer) groups will be difficult to change.

5. Attitudes that fit in with a person's needs or his view of himself are more difficult to change than attitudes that are unrelated to motivational factors. People who have low self-esteem but believe that at least they are "better" than disabled people will be difficult to convince that disabled people should be considered equal to the non-disabled.

6. Motivation to change is the final important factor. If one can induce an atmosphere that causes an individual to express a willingness to change his attitudes, attitude change will be much more likely.

Recipient Behavior

Although often not discussed, recipient behavior is probably the most important factor involved in attitude change. To change attitudes it is important to get the receiver to *do* something. Passive receipt of a message is not enough to bring about attitude change any more than it is sufficient to bring about learning in the classroom.

The following types of activities have been shown to have high levels of effectiveness in bringing about attitude change: 1) Self-examination in an attempt to understand one's beliefs, feelings, and behaviors toward a specific group will often provide insight into underlying rationalizations and will tend to make a person more willing to change his attitudes; 2) Role playing or role reversal in which a person tries to act the part of someone she doesn't like or doesn't understand, or the part of a member of a group

toward whom she has negative feelings frequently results in greater empathy and understanding and is sometimes accompanied by attitude change; 3) Public commitment to a specific attitude or action has been found to be a powerful influence on behavior because most people behave in ways that are consistent with their public commitments; and 4) Counter-attitudinal advocacy, in which a person writes and/or gives a speech expressing an attitude that is different from the one he actually holds, often results in attitude change.

THE EFFECTS OF CONTACT

The term contact is used in the present context to refer to any kind of interaction between a non-handicapped and a handicapped person. Contact sometimes results in positive attitudes, sometimes in negative attitudes, and sometimes it seems to have no effect whatsoever. The types of effects that occur depend upon many variables such as the extent of the contact, the type of interaction that occurs, etc.

Contact Variables

Seven characteristics of the contact situation appear to account for most of the specific effects that result from the interaction.

1. *Frequency of contact*. In general, the more frequent the contact between two individuals, the more positive the attitudes that result. Frequency of contact and positive attitudes are most apt to result from physical proximity at a person's place of residence, work, school, recreation, etc.

2. *Status*. The relative status of the persons who interact with one another has also been found to be important. The most positive attitudes result when the two persons have equal status. Positive attitudes can also occur when the minority group member, the handicapped individual, has higher status than the non-handicapped person. But when the handicapped person has lower or inferior status, negative attitudes will result.

3. *Type of interaction*. If the interaction is friendly, positive attitudes tend to result. If it is unfriendly or hostile, the resulting attitudes tend to be negative. Similarly, cooperative behavior in which the individuals work to achieve common goals tends to lead to positive attitudes, while competitive behavior often results in negative attitudes.

4. *Intimacy*. The closer the contact and the more that each individual gets to know the other, the more favorable the attitudes that result. Close personal contact often leads to the perception of similarities which in turn can lead to liking.

5. *Societal and institutional norms*. When the laws and regulations of a society and its leaders view integration of disabled persons with favor, it is carried out without much difficulty and has positive effects. But when the leaders of a society are negative or neutral in their points of view, the effects of contact and integration reflect their attitudes. This applies to institutions such as schools, colleges, and places of employment as well as to neighborhoods and cities.

6. *Setting*. The setting will influence the norms that prevail, the type of interaction that occurs, and the amount of intimacy that occurs. The data indicate, for example, that contact in a medical setting tends to have less positive effects on attitudes toward handicapped persons than contact in either an employment or a social setting. These differences might stem from the differences in the information provided in the different settings, the differences in status, or the type of interaction that occurs. In a work situation information is provided about the abilities and skills of the handicapped person. In a medical or rehabilitation setting, the information often relates to the inadequacies and disabilities of the handicapped person. Similarly, it has been demonstrated that contact with mentally retarded individuals in an institution often results in negative attitudes whereas contact on a camping trip results in positive attitudes toward these individuals.

7. *Perceived normality*. As indicated earlier, disabled persons are frequently perceived as different from non-disabled people. This perception often results in rejection; people who are perceived as different are usually not liked and not trusted, and frequently are feared. Consequently, a major goal of contact and integration should be to have disabled persons perceived as similar to everyone else. Data indicate that after extensive interaction under appropriate conditions, non-disabled people often forget about and fail to perceive the disabilities of their handicapped friends; they are perceived as just like everyone else.

Each of the seven conditions interacts with and is influenced by the others. The more conditions that are favorable, the greater the likelihood that positive attitudes will result from the interaction.

Information and Contact

We have seen thus far that both information and contact can have positive effects. But we have also seen that the effects are complex and not always positive. Research data have consistently indicated that when the right kind of information is appropriately presented and combined with contact under the right conditions, positive attitude changes will occur. This has been demonstrated for all types of handicaps.

ATTITUDES OF SPECIFIC GROUPS

There are several groups of persons whose attitudes toward handicapped people are particularly important, either because they interact with and influence the behavior of handicapped persons or because they have the power to control certain aspects of the lives of handicapped individuals, or both.

Relatives

The studies of family members of disabled persons have indicated that most of them tend to express warm, positive attitudes rather than negative ones. An examination of the types of contact that might be expected in a typical family situation make the favorable attitudes appear reasonable. Most of the interaction among family members usually tends to be frequent, intimate, and cooperative. The norms prevalent in our society specify and encourage positive attitudes toward members of one's family. And statuses tend to be relatively equal in most families, despite age differences.

Several other conclusions are supported by research results. Although the expressed attitudes of family members are usually positive, deeper probing often uncovers negative feelings mixed in with the positive ones. These attitudes often combine affection with resentment, helping behavior with feelings of shame or guilt, etc. These same ambivalences are often present in the attitudes of non-disabled family members toward one another. Parents' attitudes toward their handicapped children are frequently more positive than their attitudes toward other persons with the same handicap.

Professional Personnel and Staff

By professionals and staff members we mean all of those people who relate to handicapped individuals in a professional, semi-professional, para-professional or non-professional work capacity; medical personnel, rehabilitation workers, teachers, therapists, aides, etc.

Although the data resulting from studies are not always consistent with one another, several conclusions appear to be justified: 1) The attitudes of those who interact with handicapped persons in the course of their jobs are, on the average, no different from the attitudes of people with similar socio-economic backgrounds in the general population—they are neither significantly more positive or more negative; 2) The attitudes of members of these groups toward disabled people are just as variable as the attitudes of people in general, and this variation can be attributed to the effects of differing types of education, differing amounts of contact, etc.; and 3) There is some evidence of different attitudes toward handicapped persons among different categories of workers whose educational and contact experiences are quite dissimilar.

We do not know what makes a person choose a career in rehabilitation or in special education. We do not know what personality characteristics are involved, or the types and extent of contact with handicapped individuals that people in these fields had prior to choosing an occupation. Some studies have indicated that students in special education, rehabilitation, or counseling have more favorable attitudes toward disabled persons, but other research yielded no significant differences in attitudes among students majoring in other disciplines.

It is often thought that persons who have been trained to work with disabled people develop positive attitudes as a result of their training, even if they did not have such attitudes to begin with. Some studies that investigated this question reported positive effects, but many others did not find such effects.

Thus, we find that it is difficult to draw conclusions about the attitudes and behavior of professional personnel and staff members. Their behaviors will be influenced by the complex interaction of different kinds of past experiences

and factors existing in their present situations. Personality factors and institutional norms will play as important a role as professional status so that it is impossible to generalize about the attitudes of any professional group, or to predict differences among professional groups with any degree of confidence. Little can be done to change the personality or attitudes of persons who work with handicapped persons. We can, however, be more careful in the selection process, trying to choose people with appropriate attitudes for positions involving interaction with people who are disabled. We also can attempt to change institutional norms so that they serve to encourage the types of contact that lead to positive attitudes.

Employers

When comparative preferences for people with different types of disabilities were studied, it was found that the rank order of preferences shown by employers is similar to the rank order of people in general. There are occasional, minor differences from one type of job to another. Generally, people with ulcers, diabetes, loss of an arm or loss of a leg are most "acceptable." People with cerebral palsy, mental retardation or acute epilepsy are usually least "acceptable." Perhaps the major difference between attitudes of employers and attitudes of other people is the evidence that employers are reluctant to hire people who are blind or deaf even though these disabilities are rated as socially acceptable.

Research also indicates that large organizations are more willing to hire disabled people than small firms. Employers who have had previous experience with disabled persons are more willing to hire other handicapped workers. There have been widespread changes in attitudes over the past fifteen years, manifest primarily in decreasing prejudice toward people with physical handicaps involving the inability to use one or two limbs. There also has been an increase in the number of employers who hire handicapped workers, even though they still constitute a minority of all employers.

A recent important study reported a high degree of similarity between the attitudes of employers known as willing to hire handicapped persons and a random sample of other employers in the same city. This would indicate that a well planned, comprehensive campaign to increase the hiring of handicapped persons might have a good chance for success. An extensive campaign involving the integration of many different approaches and procedures is necessary to solve this difficult problem. The difficulty is indicated by data that show that even when businessmen agree to hire handicapped persons, only about one out of five who said they would, actually do so.

An additional barrier is found in the medical standards used in evaluating applicants for employment. These standards are often unrealistic, arbitrary, and not related to the capacity of the individual to perform a particular job. Furthermore they tend to emphasize liabilities and incapacities rather than abilities. Another barrier consists of the beliefs that it is *not* good business to hire handicapped people. Most employers believe that there are extra costs involved in hiring handicapped persons. They may not recognize that handicapped workers have lower rates of tardiness and absenteeism, and turnover costs are lower.

EFFECTIVE ATTITUDE CHANGE PROCEDURES: DIRECT TECHNIQUES

The major purpose of this section is to integrate and apply the ideas discussed in earlier sections of the paper by discussing techniques that can be effective in changing people's attitudes. Any one of the procedures, if used by itself, will probably have minimal effectiveness. Combinations of techniques will often be effective. But nothing will work with everyone or be effective all of the time.

Information Campaigns

Information campaigns are probably among the least effective of the attitude change procedures. For information campaigns to be effective, they have to be designed to communicate a comparatively small amount of information to a specific, carefully-defined audience. Under these conditions one must choose the medium, the message, and the source of the message so that the information will have the greatest impact. One might even make use of the two-step flow of communication idea, having the second step involve face-to-face personal contact. If all of these things are carefully done, and if, in addition, the recipient of the message is requested to make a public commitment to his or

her new attitude, a well-planned campaign can be effective.

Role Playing

Role playing can result in increased mutual understanding and increased mutual attraction. At its best, role reversal would involve extensive interaction between two persons each of whom is acting the part that he or she believes the other performs in real life. Thus, it might involve having a personnel manager play the role of a job applicant in a wheelchair while the part of the personnel manager is played by a disabled individual who attempts to treat the job applicant the same way that he has been treated in the past. Or, it might involve having a schoolteacher or school official play the role of a parent of a severely disabled child trying to convince his local school system to accept the child as a pupil. Two of the factors that are among the most important determinants of the effectiveness of role playing are the amount and type of information that is provided by the role playing experience, and the extent and type of emotional reactions generated by the experience.

Counterattitudinal Advocacy

In counterattitudinal advocacy an individual is required to prepare and give a speech or lecture advocating attitudes that are diametrically opposed to his or her own attitudes. An individual who is opposed to "mainstreaming" might be required to both write and give a speech designed to convince people to vote in favor of integration. Such a technique will be effective only if the person makes a sincere effort to carry out the assignment. But if the effort is made, and if the individual really tries to convince the audience, he may succeed in convincing himself.

Public Commitment

This refers to any situation in which a person makes a public statement either of his point of view or of his intention to do a specific thing. Recent data indicate that when this is done, the subsequent expressions of attitude and behavior tend to conform to the public statement made earlier.

When members of a group discuss and vote on an issue, most of the group members speak and act in conformity with the results of the vote. While this is most true of those persons who initially spoke in favor of the particular action, it is often true of those who voted against it. The effect is further enhanced if, after the vote, every member of the group either publicly states or signs a pledge that he or she will support the position taken.

A variation of this type of commitment that has been discussed in the recent literature on attitude change is called the "foot in the door" technique. This involves an initial attempt to get a person to do something seemingly unimportant and requiring little effort. Once the person has agreed and has done a small favor for you, the data indicate that it will often be possible for you to escalate your demands. There will be a high probability that the person will continue to accede to your requests. Thus, instead of trying to get an employer to agree to *hire* six handicapped workers, it might be more effective, initially, to ask him or her to agree to *interview* several disabled job applicants.

INDIRECT TECHNIQUES

These procedures involve doing things that are valuable in themselves and that may indirectly influence attitudes. None of them is specifically aimed at changing attitudes, but each of them will probably result in positive attitudes if they are appropriately implemented.

Integration

Having disabled people interact with nondisabled people in the school, the neighborhood, on the job, and in leisure time activities has been shown to have favorable effects on both groups. The specific effects of contact on attitudes will be mediated by the variables discussed earlier. Non-handicapped persons tend to develop positive attitudes toward disabled persons if they have extensive contact with handicapped persons of equal status, where the contact is intimate, pleasant and supported by social norms, and where the interaction is related to common goals. The contact will be more effective if it is accompanied by appropriate information being provided to the non-handicapped individuals.

Despite the proven, positive effects of integration under the right conditions, many people would prefer to have most disabled persons,

particularly those with severe disabilities or disfigurement, remain segregated. This attitude appears to be shared, at least in part, by a surprising number of professionals who work with disabled persons.

Changing Handicapped People

To a certain extent handicapped people are perceived as different because they *are* different, their handicap makes them different. But this one unavoidable difference is often enhanced by other differences that could be avoided. Often handicapped persons do not learn the same things that non-handicapped persons do. Nor do they develop the same interests. For example, a severely handicapped child who is unable to engage in sports may show no interest in any sport. This lack of sharing interests that most young boys have in spectator sports can serve to make successful interaction with non-handicapped children more difficult. On the other hand, a handicapped child who becomes an expert by memorizing rules and statistics dealing with his favorite sport will probably find it easier to relate to non-handicapped children, and may come to be valued for his expertise.

Changing the Environment

Both the physical and the social environment contain barriers that make it difficult, and sometimes impossible, for a handicapped person to "adjust." Some of the most important barriers are attitudinal. But there are also physical barriers that limit accessibility to buildings, facilities and transportation. Barriers can also be provided by rules, regulations, and laws. However, appropriate laws and regulations can also help to overcome barriers. If properly worded and enforced they can promote jobs, integration, and positive attitudes.

The physical design, location, and appearance of facilities providing services to handicapped persons also have an impact on the attitudes of non-handicapped people and on the stigma often associated with being handicapped. Buildings which appear institutional and foreboding reinforce "non-normal" stereotypes of disabled individuals. The concentration of facilities for disabled persons in one area of a city (nursing homes, halfway houses, rehabilitation centers, etc.) tends to emphasize the "ghettoization" and separateness of handicapped individuals. Even the names of facilities can communicate the hopelessness or separateness of the handicapped persons being served (i.e., Last Chance House, Charity Refuge, SOS Workshop, etc.). Much more attention should be directed at these physical factors which subtly influence the attitudes of non-handicapped persons—and ultimately the attitudes of handicapped persons themselves.

SOME NEEDED RESEARCH

Throughout this paper an attempt has been made to indicate the inadequacies of past research. The present section provides a listing of areas in which research could contribute significantly to our knowledge about attitudes toward handicapped persons and our ability to change attitudes:

1. The development of better instruments for measuring attitudes toward handicapped persons. Although some instruments have been widely used, none is universally accepted, and all have important faults. There is a need for several reliable and valid attitude tests that could be used for different purposes.
2. Comprehensive surveys of random samples of the American public in order to ascertain their beliefs and emotional reactions to handicapped persons in general and to specific groups of disabled persons. These should be continued over time so that changes in attitudes could be ascertained.
3. Careful studies of the relationships among attitudes toward different disability groups, among different disability categories (such as persons who are physically disabled, mentally ill, and mentally retarded), and among attitudes toward disability groups and toward other disadvantaged groups (ethnic groups, ex-convicts, juvenile delinquents, "hippies," etc.). What factors do all of these attitudes have in common, and in what ways do they differ?
4. Carefully controlled studies of the relationship between the attitudes and behaviors of family members and the subsequent attitudes and behavior of disabled members of the family. What attitudes and behavior can be shown to have positive effects on the overall adjustment of the disabled individual, and which factors have negative effects?
5. Careful studies of the effects of the behavior of persons who work with disabled people, particularly in hospital, rehabilitation, or

school settings, on the attitudes and behavior of the disabled persons they work with.

6. Studies of the common characteristics in the lives (education, experiences, attitudes, personalities, etc.) of severely disabled individuals who have been successful in careers.

7. Studies of the interrelationship among the beliefs that people have about disabled persons, their emotional reactions, and their behaviors in specific situations. This information could help to pinpoint situations that are most apt to evoke positive behavior.

8. The development and evaluation of several long-range programs aimed at changing the attitudes of non-disabled persons toward disabled persons by using combinations of techniques. The question to be answered is: "What combinations, of which techniques, applied by whom, to what target groups, under what conditions, are effective in producing what specific changes in behavior?"

BIBLIOGRAPHY

Although several hundred references have been used in the preparation of this paper, only a limited number of items are listed here. Most of them are reviews of the literature or general commentaries which themselves contain extensive lists of references. These items will be helpful for background reading.

Amir, Y. Contact Hypothesis in Ethnic Relations. *Psychological Bulletin* 1969, 71(5), 319-342.

Anthony, W. A. Societal Rehabilitation: Changing Societies Attitudes toward the Physically and Mentally Disabled. *Rehabilitation Psychology*, 1972, 19, 117-126.

Harth, R. Attitudes and Mental Retardation: Review of the Literature. *Training School Bulletin* 1973, 69, 150-164.

Himmelfarb, S. & Eagly, A. H. *Readings in Attitude Change*. New York: Wiley, 1974.

Johnson, D. W. Role Reversal: A Summary and Review of the Research. *International Journal of Group Tensions* 1971, 1, 318-334.

Kreisman, D. E. & Joy, V. D. Family Response to the Mental Illness of a Relative: A Review of the Literature. *Schizophrenia Bulletin* 1974, No. 10, 34-57.

Kutner, B. The Social Psychology of Disability. In W. S. Neff (Ed.) *Rehabilitation Psychology*. Washington, D.C.: American Psychological Association, 1971.

Rabkin, J. G. Public Attitudes toward Mental Illness: A Review of the Literature. *Schizophrenia Bulletin*, 1974, No. 10, 9-33.

Williams, C. A. Jr. Is Hiring the Handicapped Good Business? *Journal of Rehabilitation* 1972 (Mar.-Apr.), 38(2), 30-34.

Wright, B. *Physical Disability—A Psychological Approach*. N.Y.: Harper and Row, 1960.

Yuker, H. E., Block, J.R., & Younng, J. H. *The Measurement of Attitudes toward Disabled Persons*. Albertson, N.Y.: Human Relations Center, 1966.

PSYCHOLOGICAL ADJUSTMENT OF HANDICAPPED INDIVIDUALS AND THEIR FAMILIES

Awareness Paper based on a Paper by

Joan L. Bardach, Ph.D.
Institute of Rehabilitation Medicine
New York, New York

TABLE OF CONTENTS

	PAGE
Introduction	109
Counseling and the Course of Adjustment to Disability	109
The Role of Values in Adjustment	110
The Role of Sexuality in Adjustment	111
Effects of Appearance	111
Effects of Public Policy	112
Effects of Institutionalization	112
Psychological Adjustment and the Family	112
Counseling for Family Adjustment	113
Social Concerns	114
Health Concerns	115
Issues in Delivery of Services	115
Personnel and Training Needs	116
Conclusion	116
Suggested Readings	116

ACKNOWLEDGMENT

The White House Conference on Handicapped Individuals wishes to thank the following individual for her significant contribution to this paper:

Sondra Diamond, M. Ed.
Counselor in Private Practice
Philadelphia, Pennsylvania

INTRODUCTION

Psychologically well-adjusted persons are those who are able to accept their limitations and adapt to them. Moreover, they are also capable of recognizing their strengths and capitalizing on them. For some handicapped persons, attaining this goal is particularly difficult since acceptance of limitations often involves the recognition of substantial disability. In addition, identifying one's personal assets may conflict with a lack of self-confidence and a generally negative self-image.

The well-adjusted person must also be able to balance external societal expectations with internal desires and drives. For many handicapped persons, the difficulties of "living up" to the demands and requirements of the culture in terms of behavior, appearance, independent functioning, etc., are of greater magnitude than those experienced by non-handicapped persons.

Psychological adjustment for handicapped persons may also be complicated by feelings of dependency which sometimes grow out of the handicapped person's reliance on others for assistance and support. This physical reliance can become erroneously confused with psychological dependence. Simply because a physically or mentally disabled individual requires assistance in managing everyday affairs does not mean that he or she is psychologically dependent. Persons who are placed in the role of "caretaker" oftentimes assume psychological dependency and tend to overprotect the handicapped person.

In our society, a handicapped person is more susceptible to feelings of inferiority when he or she experiences difficulties in performing vocational and daily living tasks. The social isolation which often results from the handicap itself, coupled with insensitive public attitudes, may make it harder for disabled persons to develop meaningful interpersonal relationships. All of these areas of adjustment—the acceptance of limitations, the development of alternative capabilities, the avoidance of psychological dependency, the battle against feelings of inferiority and the quest for social integration—can result in anxieties for the handicapped person which drain valuable psychic and physical energy.

These statements regarding psychological adjustment are purposefully general, but it should also be kept in mind that the problems of psychological adjustment will differ markedly depending on the type and severity of the handicap. Other relevant considerations regarding the individual's ability to adapt to a handicapping condition include the age at onset of the condition, the ways in which the handicap impinges on the individual's productive or vocational life, the extent of disablement, and the reaction of those close to the disabled person to the presence of the handicap.

COUNSELING AND THE COURSE OF ADJUSTMENT TO DISABILITY

Counseling is extremely helpful to handicapped persons. Such assistance can aid the individual to understand his or her limitations and to identify strengths and competencies. Counseling is as important to the adjustment of handicapped persons as other forms of treatment such as psychotherapy, speech, physical and/or occupational therapy. All counselors and therapists should be made aware of the counseling needs of handicapped persons, and professionals in general should make an effort to increase the access of disabled individuals to psychological services.

Certain factors in the adjustment process must be understood in order to effectively help the handicapped person. Individuals with handicaps have a realistic problem that must be dealt with. In order to help disabled persons, the counselor needs to know what the developmental stages of adjustment to disabilities are likely to be. Knowledge in this area, however, is insufficient.

That more is known about the psychological adjustment process of persons with an acquired disability than those who are born with a handicapping condition seems to be a prevalent view. There is also limited knowledge about the effect of disabilities which have a gradual onset or which fluctuate in severity (e.g., as a result of arthritis or multiple sclerosis). The person who has a gradually disabling condition has more time to adjust to it, but he or she must adapt to the unpredictable nature of such a condition. Individuals who have fluctuating disabilities may also have a difficult time in making an adjustment. In order to make counseling more effective, much research is needed about how adjustment processes differ according to the onset, duration, nature and severity of the handicap.

For acquired disabilities, the first stage of counseling should be at the point of the onset of the handicapping condition. As is often the case when an individual receives unwanted news, the first impulse is to deny it. This rejection of the

truth is necessary to give the individual time to cope with the unwanted news. Initial denial in the early stages after the onset of the handicapping condition can be essential for the individual's emotional stability. It serves to lessen or even prevent an individual from becoming overwhelmed by his or her tragedy. Eventually, through rehabilitation, including counseling, handicapped persons learn that there are still many things they are capable of doing. As they engage in more activities, they gradually regain lost self-confidence. Inner strength grows. Over time, the individual is able to accept the truth and denial diminishes.

Acceptance of the handicap, however, may be accompanied by an increase in depression (anger turned inward) caused by the recognition of limitations. Even the presence of depression, however, may be necessary to the eventual adjustment to the handicap. A person becomes depressed when he or she has lost something important. A disability is often felt as a significant loss.

Emotionally significant occasions often seem to require a ceremony or ritual to mark them. For example, persons who complete extended psychological treatment often express a wish for some kind of graduation ceremony. When the President of the United States was assassinated, the ritual of putting on the lights of one's car developed as a symbol of mourning. In our society, mourning for the dead is initiated by a ritual—the funeral. Disabled individuals may also need to go through a period of mourning for the loss of function. Mourning may continue for the disabled person until the individual has regained enough inner strength to withstand the real loss. The presence of such depression, by itself, is not necessarily a sign of emotional difficulty. It may only mean that the person is becoming strong enough to cope with the realities of his or her condition.

In addition to depression, handicapped persons sometimes feel self-pity of a different nature than that experienced by non-disabled persons. There is evidence that this feeling is particularly prevalent among persons whose handicaps began before puberty. Self-pity in handicapped persons arises from the conflict between what they *want* to do, what they are *able* to do, and wnat they are *allowed* to do. It should be kept in mind that self-pity can be a constructive emotion which should be acknowledged and understood. Once the feeling is understood, then it can be adjusted to.

Two factors are important in predicting the duration of the adjustment process. The first factor relates to the extent of the loss. For example, adjustment may be prolonged if a significant vocational change or change in life-style is required because of a disability.

The second factor affecting the rate of adjustment to acquired disability is the personal value which the individual places on the loss. For example, for an individual whose self-confidence has been intimately connected with his or her body, a physical injury such as a disfigurement can have a profound effect. By understanding the relationship between the disability and the individual's self-image, counselors can help disabled persons in their psychological adjustment process.

THE ROLE OF VALUES IN ADJUSTMENT

Adjustment to a disability is also contingent upon the nature of the individual's self image. Some people obtain their sense of worth by comparing themselves with others. There are other people who derive their sense of worth from inside themselves. For example, persons in the latter group are not as likely to see themselves as less than "whole" if they are forced to walk with braces. Individuals who compare themselves to others (e.g. "keeping up with the Joneses") are more apt to lose self-esteem if they become handicapped.

The process of adapting to a handicap may involve changes within the value system of the handicapped person. For instance, an individual's scope of values may change if he switches jobs from one utilizing manual skills to one relying more upon his intellectual skills.

Disabled persons not only may have to change their own value systems, but they may have to contend with the conflicting value systems of their friends and families. As the values of a disabled person change, he may no longer share the same views as those held by people around him. This can produce further feelings of loss for the disabled person, thus prolonging the time necessary to adjust to the disability. Here, counseling for the family as well as for the handicapped person is essential.

In addition to the internal value system of the person, external value systems associated with socioeconomic status, sex, religion, culture, etc., are also important determinants of psychological adjustment and should not be ignored during the

counseling process. It is important to realize that handicapped persons are as guided by these societal factors as non-handicapped persons. The onset or presence of a handicap does not change these factors and they are important determinants of a disabled person's behavior and life choices.

THE ROLE OF SEXUALITY IN ADJUSTMENT

A major factor which can influence overall psychological adjustment is the ability of the handicapped person to find sexual satisfaction and gratification. Consider the problems of the cerebral palsied person whose legs are crossed and locked through spasticity; the paraplegic male who may not be able to have an erection; the paralyzed man or woman whose passive-aggressive sexual roles during love-making may have to change; or the institutionalized mentally disabled person who resides in sexually segregated wards.

In order to overcome or forestall the sexual frustrations and inhibitions which a handicapped person may feel, the individual should be helped to view himself or herself as a sexual being. In that way, feelings of self-esteem and self-confidence grow.

Some of the difficulties and solutions concerning sexuality are common to a number of handicapping conditions, and, although research in this area is still emerging, some information is available. Specific problems and steps which can be taken to ameliorate the difficulties which constrain sexual expression include:

1. *Incontinency*—This condition, which is prevalent among persons with spinal cord injuries, for instance, can be remedied by training in specific bladder-emptying procedures, urinary control devices, etc.;
2. *Impaired sensation*—For persons whose disabilities result in diminished or impaired sensation, it is possible to identify other areas of sensitivity which may contribute to sexual stimulation;
3. *Motor disabilities*—Utilizing alternate positions and techniques can be effective in circumventing problems for persons with motor disabilities. For example, where movements are weak, changing bed surfaces may maximize residual strengths (e.g. water beds);
4. *Involuntary movements*—Persons with cerebral palsy and other neurological disabilities can be taught methods of "breaking" spastic reactions, and many persons can use spasticity to increase sexual functioning; and
5. *Mental disabilities*—Persons with mental disabilities—especially those who have been institutionalized—may require training in order to understand the nature of their sexuality and in the expression of sexual needs and desires.

Sexual dysfunction may have psychological as well as physiological causes, whether a person is handicapped or non-handicapped. Both aspects must be dealt with if disabled persons are to be fully functioning sexual persons. Responding to the legitimate sexual concerns of handicapped persons requires both knowledge and skilled psychological service providers.

As one step in dealing with these sexual concerns, training workshops for professionals have been set up. Often handicapped persons themselves have participated. Though these workshops do not train sexual counselors, they are designed to give factual information and to help participants become aware of their own attitudes concerning the wide variety of human sexual behavior that exists.

Formal workshops such as Sexual Attitudes Reassessment Seminars (SARS) exist. These workshops have been quite successful in reducing anxiety concerning sexual matters and in imparting information. Seminars, aimed at effectuating sexual adjustment, can contribute to increased mental health.

EFFECTS OF APPEARANCE

Persons whose handicaps are visible to those around them face problems of psychological adjustment. They are made to feel different and often, therefore, feel inferior to non-handicapped persons. Conversely, those people whose handicaps do not show may have problems because the expectations of others may exceed their capabilities. These handicapped persons may also feel they have something to hide, causing feelings of shame and rejection.

There are conditions that alter a person's ability to express feelings. Scars on the face, as from burns or surgery; the "masked face" which is common in Parkinson's disease; an inability to express emotions with bodily gestures associated with paralysis; an inattentive or distracted state brought about by heavy medication; and a lack of coordination as in cerebral palsy, all pose barriers to communication. Others may misinterpret

bodily or facial expressions and, therefore, the feelings of such persons. Interactions between family members and friends can be hampered and communications misunderstood.

EFFECTS OF PUBLIC POLICY

Public policy can also have an impact on the self-image and, therefore, the psychological adjustment of handicapped persons. For example, lack of accessible transportation systems substantially hampers the ability of handicapped persons to travel conveniently. Failure to enforce laws requiring barrier-free design in public buildings can result in making access to such buildings almost impossible for handicapped individuals. The isolation of mentally disabled persons in custodial facilities can affect their ability to resume normal lives in their home communities. Finally, the exclusion, segregation, and labeling of handicapped children in the public schools potentially adds to the development of a negative self-image.

EFFECTS OF INSTITUTIONALIZATION

Institutionalizing a handicapped individual affects psychological adjustment because it places the disabled person in an unnatural and dependent environment. Frequently, residents are treated as if they are all alike; their individuality is ignored. As a result, self-esteem suffers and adjustment is hampered.

Mentally ill persons who have spent long periods of time in state hospitals become dependent on their surroundings, and their ability to cope with the pressures of everyday living diminishes with each year they remain institutionalized. Though their mental illness is reduced with time, there is a strong possibility that they will emerge from the experience with other functional handicaps acquired during the period of prolonged isolation. When they return to the community, they must be taught to "navigate" in this new environment—to participate in more normal social and family relationships.

PSYCHOLOGICAL ADJUSTMENT AND THE FAMILY

The process of adjustment to disability is also experienced by the disabled person's family. For example, parents who bring a handicapped child into the world often experience a shock that triggers the same reactions of denial and depression which disabled individuals themselves feel.

The family's reaction to the disabled child significantly affects his or her psychological adjustment. It is in the family unit that all children develop the self-image that will dictate later social interactions. In the case of children with a handicap, the response of the parents toward that handicap is crucial in determining how the child will regard himself or herself in later life. If the handicap is over-emphasized by the family, then other aspects of the child's development may be slighted. If, in addition, the handicap is reacted to as something unwanted and something that makes the child more vulnerable, the child may develop feelings of inadequacy and inferiority. This anxiety may in turn cause the child to avoid risks or challenges; his or her initiative may be diminished.

Often to hide anxiety, feelings of disgust, pity and the like, the family may present a "blank face" to the handicapped child. This lack of expression hampers the ability of the child and those around him to communicate with one another. This, in turn, limits the handicapped child's knowledge of the feelings of others, and reinforces his social isolation. Work with parents and others who come in contact with the handicapped child should be aimed at improving communication, thereby assisting the process of socialization.

Parents may search for reasons to explain why their child is handicapped. If the child became handicapped as a result of an accident or a disease, the parents often feel that they were at fault. If the handicap was congenital, they may tend to assign the cause to heredity, sometimes blaming themselves or one another. Guilt in one form or another is almost always felt by parents of disabled children.

In the mental health literature describing the causes of mental illness, the finger has traditionally been pointed at parents as the prime agents responsible for their child's disability. Though more recently some of these theories have been called into question, some parents are still made to feel guilty and are many times dismissed as potential participants in the therapeutic process.

Parents want to give their handicapped child the best care they can, but many times this places extra burdens on families—especially those where there are other children. Parents love their handicapped child, but they may also experience guilt about their feelings of being "put-upon." Such

parents may translate this guilt into hostility toward other parents, toward school authorities, toward each other, or toward society in general. Such reactions naturally add stress to the family unit.

Parents may over-react to the handicapped child, either by being too attentive and protective or by being excessively critical and demanding. In either case, the child is placed at a disadvantage—even though the parents' behavior is not intentional. The over-indulged child does not learn to tolerate frustration, nor does he or she learn about the rights of others. The overly criticized child develops a sense of inadequacy greater than the reality of his or her handicap.

Some parents over-protect their handicapped child because they inappropriately see their child as weak and easily harmed. They feel, for instance, that attempts at discipline might result in aggravating the effects of the handicapping condition.

The reactions of parents to physically or mentally handicapped children are similar to those of parents of non-handicapped children. All parents tend to be concerned about their child's health and worry about injury and accident. Parents of handicapped children, however, may feel such things even more, and can become excessively worried over the slightest symptom.

Most parents have conflicts concerning when and how much independence to give their children. These dilemmas may be even greater for parents with disabled children. For the non-handicapped child, there are fairly well-defined steps which mark evolving independence—beginning with attendance at school, day camps during the summer, attendance at away-from home summer camps at later ages, etc. The learning and developmental milestones for handicapped children may not follow such a regular pattern. Thus, parents may be less sure at what age their child should know certain facts or at what age their child should be able to perform certain tasks.

Like other parents, those of handicapped children see their children as extensions of themselves. Parents of a physically disabled child might tend to compensate for their child's physical limitations by pushing the child's intellectual accomplishments. Parents of mentally retarded children may have an especially difficult time accepting their retarded child as a person with a distinct personality, yet with limited intellectual potential. If the child is mentally ill, then the parents are likely to look for some "sickness" in themselves or in the immediate environment.

Sometimes parents look to their non-handicapped children to make up for lessened capacities in handicapped siblings. This may place an extra achievement burden on the non-handicapped child. Non-handicapped children may also be jealous of the added attention the parents give to their handicapped brother or sister, yet they are supposed "to understand" and to love the handicapped child. Jealousy, as well as the feeling of responsibility to help in the care of the handicapped child—even to the point of assuming a surrogate parent role—may lead to resentment and feelings of guilt.

Relationships among family members may also also be complicated by feelings of guilt associated with an event which precipitated the handicapping condition. For example, a twenty year old man had a car accident following an argument with his father. The accident left him paralyzed from the waist down. Even years after the accident, whenever the son saw his father, the son had to reassure his father that everything was fine. The son became unable to discuss his worries or to ask his father for advice for fear that his father would once again be overcome by his feelings of guilt.

Family members may also be reluctant to discuss the prognosis of the handicapped person's physical or mental disability with one another. Knowledge regarding the condition may be withheld by the handicapped person or by family members, and communication, therefore, blocked.

All of the regular stresses experienced by families, then, *may* be magnified in the family of a handicapped person. The anxieties produced by such stress may influence the family's behavior and affect the adjustment of the handicapped person as well as that of the family.

COUNSELING FOR FAMILY ADJUSTMENT

Counseling or other psychological services are very useful in reducing the stresses placed on a family when one of its members is or becomes handicapped. Counseling will help the family to seek outside interests in order to reduce possible social isolation. Counseling also helps parents to distinguish between a handicap and an illness. Because their child is handicapped, it does not mean that he or she is ill. Finally, counseling will help parents to see the similarities between their

disabled child and non-handicapped children. For instance, the child has the same need for love, for socialization and for achievement that other children do.

In dealing with families, it is important to create an atmosphere that encourages communication among family members, including communication with the handicapped family member. Skilled counseling professionals can encourage mutual respect and improve communications for all involved.

The content of counseling assistance will undoubtedly change as the handicapped child grows older. When the child is very young, parents are generally concerned with physical development, methods of toilet training, the development of self-help skills, speech, etc. Parents of a school-age child want guidance in finding the best school setting for the child. At that time they also have many questions concerning the child's cognitive development. When the child becomes a teenager, questions concerning social, sexual, and vocational development arise.

Parents need general guidance in helping them understand their child's abilities and limitations so that they can realistically plan for their child's future. They also want help in developing adequate plans for the care of the handicapped child after their death. Quite often, these issues can be dealt with in a closed, short-term group made up of parents whose discussion is guided by a trained leader. The sharing of anxieties, frustrations and possible solutions with other parents of handicapped children helps parents to realize they are not alone. This supportive atmosphere gives them emotional solace which helps to ease stress in the family.

Besides this small group therapy, there are other forms of counseling for family members. One recent development is the "Seminar in Personal Functioning" run jointly by a physician and psychologist. The seminars focus on topics like motor functioning, sensation, sexual functioning, intelligence, emotional disturbance, etc. The objective is to communicate important developmental information in a warm and caring atmosphere. Both the information given and the family's emotional reactions to that information are discussed. In some cases, having disabled persons with their families during the seminar can aid communication between handicapped individuals and their families.

To lead seminars of this type takes great skill. It requires techniques different from group psychotherapy. Training for this kind of leadership is lacking in our universities. Additional training programs are needed in order to expand the number of people who can conduct such groups.

Another innovative approach would be to establish a service and advocacy agency for families in each community. If these Departments of Family Education were established, they could also assist parents of handicapped children. These agencies could provide information regarding handicapping conditions and could also help families secure needed services. Educational programs using lectures, movies, etc., on various handicapping conditions could be used as informational devices.

Counseling should not be strictly limited to immediate family members, but should also include other close personal friends where appropriate. Thus, a person who is engaged to be married to a handicapped person, a close friend, or any major, caring figure should be given the same consideration for counseling as a close family member.

Parents and other family members may need counseling when a disabled family member requires residential care or is returning from residential care after a long period of time. For example, the decision to place a person in an institution must first be weighed carefully to assess the relative advantages of such placement to both the family and the disabled person. If the decision is made to place the child or adult in an institution, then the family may also need counseling in order to facilitate the transition from the home to the institution.

The decision to place the disabled person back into the family environment after a prolonged absence must also be made carefully, determining whether the family can provide the needed support and whether the disabled person can best be served in this environment. Keeping in mind that many disabled persons are especially susceptible to the external expectations set for them, placement in an overprotective family may not be conducive to rehabilitation. If the person returns home, the family may require counseling to cope effectively with the situation.

SOCIAL CONCERNS

The best fitted and most functional brace in the world is no good if its owner never uses it. Refusing to take advantage of such assistance can be influenced by a variety of social factors

which contribute to the handicapped person's attitude. If a person is made to feel that a visible handicap is peculiar, then he or she may shun any exposure which calls attention to the problem. In order for the individual to use the brace, he or she must be prepared to risk potential rejection by individuals in the community at large.

Handicapped individuals are often discriminated against, as are some racial and ethnic groups. These prejudicial attitudes affect the psychological adjustment of handicapped persons and can potentially diminish their ability to be productive citizens. For example, many employers still are reluctant to hire handicapped persons. Rather than refusing to employ the individual because he or she is handicapped, some employers are more apt to blame conditions "beyond their control," such as insurance rates, etc. All of this adds up to waste—both in human and economic terms.

A disability can also affect the role that a handicapped person plays in society. Fewer roles may be opened to the individual, and many times the only role left is that of a dependent, "sick" person. In general, handicapped people not only have fewer roles, but they have fewer social relationships and contacts with the community. Institutionalized people are frequently given no role other than "patient." This role restriction keeps many handicapped persons dependent unnecessarily.

Disability may also restrict the roles which a handicapped person can play in the family. The woman whose disability makes it impossible for her to perform regular household tasks will be under stress and so will the whole family until adjustments can be made. Traditional male/female roles may also shift. Men used to a more typically masculine profession, such as fireman, may have to make a transition to a more conventionally feminine vocation, such as clerk/typist.

Another role-problem faced by disabled persons results from society's conflicting attitudes. The handicapped person is supposed to "accept" his or her disability, yet struggle to overcome it. Handicapped people are frequently subject to public sympathy, but private feelings of rejection.

Social forces in our culture affect the handicapped person's ability to maximize his or her independence. These forces affect such things as employment opportunities and opportunities for social integration. Limits on the roles handicapped persons can play constrain their daily lives and hamper their adjustment.

HEALTH CONCERNS

Those involved in the treatment of handicapping conditions should be attentive to the social and psychological aspects of the disability as well as purely medical considerations. Medical treatment itself requires coordination with psychological services. The success of most medical interventions will be contingent on a careful assessment of the potential psychological consequences of treatment. For instance, the acceptance of a brace by a handicapped person is influenced by: the person's ability to view the brace as a part of his or her own body; the person's self-picture; the particular meaning of the brace to the person (i.e., is it seen as calling attention to the handicap, or as a tool to aid functioning?); the attitudes of the person's family; and many other factors.

It should be kept in mind that many physically handicapped persons are preoccupied with their "physical selves" and, therefore, with their health. This orientation needs to be acknowledged by medical and other professionals, who should be sensitive to this understandable phenomenon.

ISSUES IN DELIVERY OF SERVICES

As with non-handicapped individuals, changes occur in the psychological adjustment of a disabled person when events such as a death in the family place him or her under stress. Changes in the family make-up, like marriage of a sister or brother, death of a parent, etc., can reactivate the need for counseling for a handicapped person.

In addition to adapting to the changing needs of the handicapped person, the system of psychological services should also be responsive to the development of new treatment techniques, service settings, and benefit programs. We need improved methods of disseminating information regarding these recent advances, and evaluation and outcome studies which can assist in determining which new techniques are most effective.

It is finally being recognized that, as with all other people, the psychological needs of handicapped persons span their life-time. A system of flexible, life-time services, would make it possible to prevent further disability in some cases. Longitudinal studies are also needed to assist the designers of service delivery systems in long-term care. In the long run, the cost of services can be

lessened and human suffering can be reduced at the same time.

Some would also suggest that the role of families in providing care, attention and support to their handicapped children, spouses, etc., should be recognized by society as a positive social good (both in a cost-benefit and humanitarian sense) and given a monetary value as well as a normative or moral value. Such benefits might include tax rebates and/or supplemental financial support to the family. This would have the advantage of obviating the need in some cases for out-of-home placement and of providing many genuinely concerned families with additional resources needed to meet the special needs of handicapped persons, including psychological counseling.

Finally, the need for accessible and continuous counseling services can not be stressed enough. All current psychological services such as community mental health centers, private practitioners, etc., must establish outreach services to assure that handicapped persons receive the support they require.

PERSONNEL AND TRAINING NEEDS

The psychological adjustment of physically and mentally handicapped individuals and their families is very complex. No one professional group is necessarily capable of handling all the aspects of satisfactory adjustment. A team, made up of individuals trained in a variety of different disciplines is needed.

Handicapped people themselves can be employed to provide guidance. They can share information regarding: consumer and legal rights, management of living situations, social opportunities, personal care techniques, sexual counseling, etc. Moreover, handicapped persons can make important contributions in the service delivery system as professionals.

Psychological services for disabled people should focus on the development of competencies necessary for living in the community. Developing those competencies will markedly influence the handicapped person's self-esteem and will help to maximize his or her independence. There is an ongoing need for counselors and other specialists trained in the provision of such services.

CONCLUSION

Many factors have an impact on the psychological adjustment of handicapped persons and their families:

1. The age at onset, duration, nature and severity of the handicap;
2. The personal value system of the handicapped person and his family;
3. The ability of the handicapped person to experience sexual gratification;
4. The ways in which the handicap alters the person's appearance and hampers his or her ability to communicate;
5. The conduct of public policy in such areas as transportation and architectural accessibility, public education, and treatment;
6. The extent to which handicapped persons are isolated from the rest of society;
7. The ways in which family members and other individuals close to the handicapped person respond to the presence of the disability;
8. The magnitude of discrimination and prejudice displayed by persons in the handicapped person's social and vocational environment;
9. The extent to which medical intervention is sensitive to the psychological aspects of handicapping conditions;
10. The presence of trained and sensitive professionals in the psychological services delivery system;
11. The responsiveness of the delivery system to new advances and innovative techniques; and
12. The presence of comprehensive counseling services for the handicapped person and his or her family.

SUGGESTED READINGS

GENERAL

Barker, R. G., Wright, B. A., Meyerson, L., & Gonick, M. R. *Adjustment to Physical Handicap and Illness: A Survey of the Social Psychology of Physique and Disability.* Social Science Research Council Bulletin 55, New York, 1953.

Cobb, B. (Ed.) *Medical and Psychological Aspects of Disability.* Springfield, Illinois: Charles C. Thomas, 1973.

Garrett, J. F., & Levine, E. S. *Psychological Practices with the Physically Disabled.* New York: Columbia University Press, 1962.
Goffman, E. *Asylums.* Garden City, New York: Anchor Books. Doubleday & Company, Inc., 1961.
Ince, L. P. *The Rehabilitation Medicine Services.* Springfield, Ill.: Charles C. Thomas, 1974.
Neff, W. S. *Rehabilitation Psychology.* American Psychological Association, Washington, D.C., 1971.
Weisman, A. D. *On Dying and Denying.* New York: Behavioral Publications, 1972.
Wright, B. *Physical Disability—A Psychological Approach.* New York. Harper & Row, 1960.

CHILDREN

Non-Technical

Beck, H. L. Group Treatment for Parents of Handicapped Children. DHEW Publication No. (HSM) 73-5503, May, 1973, Superintendent of Documents, U.S. Government Printing Office, Washington, D.C.
Stern, E., with Castendyck, E. *The Handicapped Child: A Guide for Parents.* New York: A. A. Wyn, Inc., 1950.

Technical

Trapp, E. P., & Himelstein, P. (Eds.) *The Exceptional Child.* New York: Appleton-Century-Crofts, Inc., 1962.

SEXUALITY

Non-Technical

Enby, G. *Let There Be Love.* New York: Taplinger Publishing Co., 1975.
Mooney, T. O., Cole, T. M., & Chilgren, R. A. *Sexual Options for Paraplegics and Quadriplegics.* Boston: Little Brown & Co., 1975.

Technical

Cole, T. M., Chilgren, R., & Rosenberg, P. New Program of Sex Education and Counselling for Spinal Cord Injured Adults and Health Care Professionals. *Int. J. Paraplegia*, 1973, 11, pp. 111–124.
Griffith, E. R., Tomko, M. A., & Timms, R. J. Sexual Function in Spinal Cord-Injured Patients: A Review. *Arch. Phys. Med. & Rehab.*, Dec., 1973, Vol. *54.*
Griffith, E. R., & Trieschmann, R. B. Sexual Functioning in Women With Spinal Cord Injury. *Arch. Phys. Med. & Rehab.*, Jan. 1975, Vol. *56*, No. 1, pp. 8–13.
Griffith, E. R., Trieschmann, R. B., Hohmann, G. W., Cole, T. M., Tobis, J. S., & Cummings, V. Sexual Dysfunctions Associated with Physical Disabilities. *Arch. Phys. Med. & Rehab.*, Jan. 1975, Vol. *56*, No. 1, pp. 8–13.
Held, J. P., Cole, T. M., Held, C. A., Anderson, C., & Chilgren, R. A. Sexual Attitude Reassessment Workshops: Effect on Spinal Cord Injured Adults, Their Partners and Rehabilitation Professionals. *Arch. Phys. Med. & Rehab.*, Jan. 1975, Vol. *56*, No. 1, pp. 14–18.
Heslinga, K., Schellen, A. M. C. M., & Verkuyl, A. *Not Made of Stone.* Springfield, Ill.: Charles C. Thomas, 1974.

RECREATION

Awareness Paper based on a Paper by

David C. Park
George Washington University
Washington, D.C.

TABLE OF CONTENTS

PAGE

INTRODUCTION 121

Recreation and Leisure in Society 121
Recreation for Handicapped Individuals 122

HISTORICAL DEVELOPMENT 122

Organizational and Other Efforts 122
Federal Activity 124

STATE OF THE ART IN RECREATION FOR HANDICAPPED INDIVIDUALS 125

Residential Facilities 126
Community Based Programs 126
Other Programs 127

ISSUES IN MEETING RECREATION NEEDS 128

Continuum of Services 128
Funding Considerations 128
Architectural Barriers 129
Transportation Barriers 129
Communication Barriers 129
Attitudinal Barriers 129
Manpower Needs 129
Research Needs 130
Leisure Education 130

CONCLUSION 131

BIBLIOGRAPHY 131

ACKNOWLEDGMENT

The White House Conference on Handicapped Individuals wishes to thank, for his significant contribution to this paper:

Dr. Julian U. Stein
Programs for the Handicapped
American Association for Health,
Physical Education and Recreation
Washington, D.C.

INTRODUCTION

Recreation and leisure make up some part of the life-style of virtually everyone in this country regardless of age, sex, profession, region, or ethnic background. Generally, most of us tend to view recreation as a positive pursuit. At the same time, however, there are variations in the priority which recreation has vis-a-vis other activities in our daily lives. Depending on the nature of other pressures, recreation may or may not be a major force in our lives—although an important element in any balanced existence.

This paper is concerned with the recreation and leisure needs of persons with handicapping conditions. The discussion is premised on the assumption that recreation and leisure activities can assist handicapped persons to live with dignity, and to function as independently as possible. Participation in such activities can also accelerate the integration of handicapped persons into the community, thereby reducing isolation and stigma. Further assumptions include:

- Recreation and leisure activities and opportunities are an integral part of life for every individual including those with handicapping conditions;
- Recreation and leisure activities should be valued as highly as other elements of human experience including work;
- Recreation should be an integral part of educational, social, vocational, and rehabilitation programs for adults as well as children; and
- All people, including handicapped individuals, need to be made aware of the important role which creative leisure activities can play in the enrichment of human existence.

In order to bring these principles to bear on the needs of handicapped persons, this paper:

1. Explores the special recreational and leisure-time needs of handicapped individuals;
2. Outlines general recreation needs for *all* people and points out the special problems in meeting the needs of handicapped individuals;
3. Analyzes the role which recreation services play in the educational, vocational, and social development of handicapped individuals;
4. Reviews the state of the art in providing recreation services in hospitals and institutions;
5. Examines the employment opportunities for handicapped persons in the provision of recreation services;
6. Discusses methods for making facilities, recreation areas, and equipment accessible to and usable by handicapped individuals;
7. Outlines current and needed legislation to create equal opportunities for handicapped persons in recreation;
8. Assesses current efforts to provide necessary manpower training to meet the recreation needs of handicapped persons; and
9. Describes the continuum of recreational activities necessary to enable individuals with varying levels of disability to participate to the maximum extent possible in community-based leisure programs.

Recreation and Leisure in Society

Our concepts of play, recreation, and leisure have changed through the ages. The term "leisure" comes from the Latin *licere,* meaning *to be permitted.* In earlier times, it described a way of living or a state of being reserved for a select few who were able to contemplate their relationship to God and society without the press of other responsibilities.

With the heavy emphasis placed on work during the Industrial Revolution, the concept of free or leisure time became equated with idleness and was seen as wasteful. Even though times continue to change, society still places high premiums on work and on productive activities which contribute to the economy.

However, during the 20th century, the recreation movement—both public and private—has grown steadily in the United States. As technology and automation have reduced the number of hours one must work to make a living, renewed interest has been kindled in the role and value of leisure time in enhancing the quality of life. Governments at local, state, and national levels are beginning to recognize that what people do during their leisure time may have a direct impact on the health and vitality of the society. Thus, recreation services are becoming an integral part of human services delivery systems.

Recreation is a relative concept, and what might be recreation to one person may be drudgery to another. For some, recreation means activity and action; for others it may mean more passive pursuits. However, the common goal is enjoyment and personal satisfaction. Leisure

activities provide relaxation, renewal and balance in our lives. Recreation should not be conceived of as a limited set of specific activities, but rather as a range of endeavors which meet individual needs. Recreation is not just a pleasant indulgence—it is a crucial element in a full and rewarding life.

Recreation for Handicapped Individuals

Recreation and leisure are a necessary part of human development in that they enable individuals to explore their full potential. This goal is equally important to handicapped individuals and, therefore, recreation should be included in the range of programs available to such persons. It can be argued that in some instances, the provision of recreation services is even more important to persons with disabilities since many are confronted with *enforced* leisure, either as a result of their disability or continuing discrimination in the job market.

The current state of the art in recreation for handicapped individuals, though still inadequate, is improving. Over the past few years, an increasing effort has been made to call attention to the need for and the importance of recreation opportunities for disabled persons. For example:

- The number of articles describing new techniques in recreation services which appear in professional journals and newsletters is growing; books, monographs and other materials on the subject are also becoming more available;
- Audiovisual and media presentations provide information regarding ongoing recreation programs and describe the methods and adaptations necessary to meet individual needs;
- Information systems and materials centers such as Therapeutic Recreation Information Center (TRIC), and Physical Education and Recreation for the Handicapped: Information and Research Utilization Center (IRUC) have been established to provide information and materials regarding recreation services;
- Special programs at professional conferences, conventions, and meetings provide a means to share information about recreation programs, needs and problems; and
- Results of research and demonstration projects are being reported on an increasing basis.

Innovative and creative programs are being conducted in many places. However, if one looks at the total scope of opportunities for *all* handicapped persons, it must be concluded that too few handicapped persons are currently being served. Too many programs suffer from a lack of adequate funding and insufficiently trained leadership. Many programs still operate on a separate or segregated basis which tends to perpetuate the concept that handicapped people are different and unable to participate in the "mainstream" of community life. Additionally, disabled persons are rarely involved at decision and policy-making levels regarding recreation programs and activities. It is also unclear to what extent handicapped persons participate in informal, less organized recreation activities as opposed to formal, structured, and highly organized programs sponsored by public and private organizations.

HISTORICAL DEVELOPMENT

Organizational and Other Efforts

Prior to the last twenty-five years, few opportunities existed for handicapped persons to engage in recreation and leisure activities. Individuals who were able to find opportunities were generally those few who had the capacity to generate opportunities for themselves and to overcome the many barriers and obstacles placed before them. This picture began to change with the introduction of wheelchair basketball into rehabilitation programs for veterans injured during World War II.

Subsequently, in 1952, the Recreation Center for the Handicapped was established in San Francisco to serve individuals who could not gain access to local park and recreation programs. The Center's program includes services for the most severely disabled, and individuals do not have to be ambulatory or competent in verbal communications. The Center provides services for all age groups and types and degrees of handicaps. Programs and activities stress age appropriateness, client interest, and functional abilities—not categorical labels. The Center utilizes sites all over the state of California and in adjacent states in order to broaden recreation opportunities. Programs to transfer Center participants to other community recreational services have been successful. The Center has grown from six participants in 1952 to over 1,300 today and the

model has been replicated in many areas of the country.

Voluntary health organizations and special interest groups concerned with specific disabling conditions also played a role in expanding recreation services for handicapped persons. For example, the National Association for Retarded Citizens promoted recreation through local associations and informational publications. The National Easter Seal Society for Crippled Children and Adults became involved in recreation and camping programs through local affiliates. More recently, such organizations as the United Cerebral Palsy Association, the Epilepsy Foundation of America, and the Association for Children with Learning Disabilities have actively supported the expansion of a variety of recreational and leisure activities and programs.

Recreation professionals became involved in providing services to handicapped persons in the middle 1940's in hospitals and institutions as part of rehabilitation and treatment services. In fact, the development of specialized recreation services began in such facilities and are still an important part of institutional treatment programs. In 1948, the American Recreation Society, the professional recreation organization at the time, created a Hospital Recreation Section to serve recreation personnel involved in these rehabilitation programs. This professional development was further advanced by the American National Red Cross which created full time positions for hospital recreation workers in military hospitals, and by the Veterans Administration which established recreation services as part of its Hospital Special Services Division.

Organizations such as the National Association for Recreational Therapists and the Recreation Therapy Section of the American Association (now Alliance) for Health, Physical Education, and Recreation also promoted recreation services in hospitals and developed professional standards. The National Recreation Association promoted services for handicapped individuals through community recreation departments by establishing a Consulting Service on Recreation for the Ill and Handicapped.

In 1966, the National Recreation Association, the American Recreation Society, the National Association for Recreation Therapy, and others merged to form the National Recreation and Park Association (NRPA). One branch of NRPA, the National Therapeutic Recreation Society (NTRS), is specifically concerned with the development of total recreation services for persons who are mentally or physically disabled. NTRS has helped to develop the field as well as the concept of therapeutic recreation and has advanced standards to guarantee the quality of services delivered.

To expand therapeutic recreation beyond rehabilitation programs in hospitals and institutions, NTRS, working with other branches of NRPA, has aided in the development of community-based recreation programs for handicapped persons. As a result of the work of these national organizations, many local recreation professionals are beginning to recognize that their public responsibility extends to *all* persons in the community–including handicapped individuals. This recognition has led to the development of numerous innovative local programs. However, there is still significant work to be done to increase the coverage of such programs.

The Joseph P. Kennedy Jr. Foundation has also made contributions to the development of recreation services for handicapped individuals. In the early 1960's, the Foundation recognized that physical education and recreation for mentally retarded persons were important factors in their development. The Foundation provided matching funds to ten community recreation departments to develop summer day camp programs for retarded children. Since that time, many of the original pilot programs have expanded from summer day camps to year round programs and, subsequently, to total recreation programs for retarded persons and other groups of handicapped individuals as well. These early model programs have stimulated the development of other recreation programs for mentally retarded and physically disabled individuals in communities and municipalities around the country. The Foundation has also provided funding for inservice training workshops and seminars, scholarships for graduate study, matching grants for day camp programs, and the development of programs such as the "Special Olympics" and "Families Play to Grow."

In addition, the Kennedy Foundation supported a three year grant to the American Association (now Alliance) for Health, Physical Education, and Recreation (AAHPER) for the "Project on Recreation and Fitness for the Mentally Retarded." This project included leadership preparation, program interpretation, and research. It was expanded by AAHPER in 1968 to a full-time unit on programs for the

handicapped to deal with physical education, recreation, and related activities for mentally and physically handicapped persons. The unit has provided guidance and leadership to the entire country in physical education and recreation services for handicapped persons.

Federal Activity

Federal legislation and programs have increasingly recognized the value of recreation as a component of services to handicapped persons. Perhaps the first Federal agency to recognize the need for recreation was the Division of Vocational Rehabilitation. In the early 1960's, the *Vocational Rehabilitation Act* (VRA) identified recreation for handicapped persons as a specific target for training funds. The first master's degree programs in therapeutic recreation developed with VRA funds paved the way for current training programs in the field. The *Vocational Rehabilitation Act* has also provided funds for research into the role of recreation in the vocational rehabilitation process.

In 1967, a provision titled "Research and Training in Physical Education and Recreation Programs for Mentally Retarded and Other Handicapped Children" was included in Title V of Public Law 90-170. This section subsequently became part of the *Education for Handicapped Children Act* which is administered by the Bureau of Education for the Handicapped (U.S. Office of Education, Department of Health, Education and Welfare). This provision supports advanced training of specialists in recreation and physical education for handicapped children, and demonstration projects in these areas. This section became the single largest funding source specifically related to physical education and recreation for handicapped children and youth.

The overall statute was again amended in 1975 by Public Law 94-142 *(Education for All Handicapped Children Act of 1975).* New language in the Act further commits the Federal government to the support of physical education and recreation in special education programs. Special education has been defined in the legislation as:

> . . . specially designed instruction, at no cost to parents or guardians, to meet the unique needs of a handicapped child including classroom instruction, instruction in physical education, home instruction and instruction in hospitals and institutions.

The Act further defines "related services" as:

> . . . transportation, and such developmental, corrective, and other supportive services (including occupational therapy, recreation, and medical and counseling services) . . .

The Congress has made its intent clear—physical education, recreation, and related activities are to be integral parts of educational programs for every handicapped child regardless of the type or severity of the condition.

Another Federal funding source for recreation programs is the *Developmental Disabilities Services and Facilities Construction Act* (Public Law 91-517). This Act, administered by the Developmental Disabilities Office in the Office of Human Development, Department of Health, Education and Welfare (HEW), provides Federal support for a wide range of services for developmentally disabled individuals. Recreation and transportation are two services specifically mentioned. Ninety percent of the funds provided through P.L. 91-517 are allocated to States based on the provisions of comprehensive State plans for developmentally disabled persons. Even though recreation is a specific service mentioned in the Act, it appears that only a few states are using these monies to fund recreation services at a significant level.

Other Federal statutes either directly or indirectly have an impact on recreation and leisure programs for people with disabilities. Public Law 90-480 *(Architectural Barriers Act of 1968)* states that any building constructed or renovated in whole or in part with Federal funds *must* be made accessible to and usable by physically handicapped persons. (Similar State laws are in existence in all fifty States.) Specifically, this Federal law impacts on a number of Federal agencies administering recreation programs. For example, it impacts on the management of the Federal Land and Water Conservation Fund administered by the Bureau of Outdoor Recreation in the Department of Interior. The Fund provides matching grants to States and localities for planning, acquisition and development of public outdoor recreation areas and facilities. All development projects submitted to the Bureau of Outdoor Recreation (BOR) are reviewed to assure that use by handicapped persons is taken into consideration in the project design and that all projects comply with P.L. 90-480. BOR is also working to ensure that

existing recreation buildings and facilities are accessible and usable by handicapped persons.

Further, Public Law 88-29, approved by Congress in 1963, affirmed the policy that *all Americans* should be assured adequate outdoor recreation resources. There has been no question that the words "all Americans" referred to aged and handicapped persons and their rights to outdoor recreation opportunities. To reinforce this policy, BOR's Nationwide Outdoor Recreation Plan of 1973 called for better coordination of recreation resources and for the development of planning and operational strategies to facilitate the development of accessible programs and facilities to serve handicapped persons.

The Federal Community Mental Health Centers Act of 1963 authorized allocation of construction and staffing grants for the development of comprehensive mental health centers in local communities. This Act includes "partial hospitalization" as one of the mandated services which each center must provide. Partial hospitalization is a general term referring to a variety of rehabilitation and therapeutic services which aid mentally ill persons in making the transition from in-patient care to normal community living. Most partial hospitalization programs include recreational activities as components necessary for reintegration of mentally ill persons into the community and as an important tool in the resocialization of such persons.

Litigation over the last five years has included recreation services as part of "right to treatment" decisions. Notable among these cases has been *New York Association for Retarded Children and Parisi v. Carey* and *Wyatt v. Stickney* in Alabama. A consent agreement signed in a Nebraska "right to treatment" case *(Horacek v. Exon)* also has implications for community recreation programs. The Nebraska decision conceivably may establish the "right to community services" for retarded individuals. The judicial order in the case places responsibility on community agencies for the provision of services to retarded individuals. The agreement affirms that ". . . all mentally retarded persons have the same constitutional rights as do all other persons who are residing in the United States of America and in the State of Nebraska."

Federal policy in the area of recreation for handicapped persons has also been influenced by a number of special national committees. The President's Committee on Employment of the Handicapped, the President's Committee on Mental Retardation, the President's Council on Physical Fitness and Sports, and the National Advisory Committee on the Handicapped are among groups that have been involved to various degrees.

In 1971, under the auspices of the Social and Rehabilitation Services Administration (in HEW), the President's Committee on Employment of the Handicapped and the National Recreation and Park Association jointly conducted a project to explore the potential for employing handicapped persons in the park and recreation field. Following this project, the President's Committee created a standing committee on recreation and leisure. In the past three years this committee has been active in bringing consumer advocates together with recreation professionals to promote improved and expanded services for handicapped persons.

Another Federal agency that has demonstrated specific interest in recreation is the Department of Housing and Urban Development (HUD). HUD recently funded a nationwide study of the accessibility of outdoor environments and recreation facilities which was conducted by the American Society of Landscape Architects. Based on the results of the study, a booklet entitled "Barrier Free Site Design" has been developed and is being circulated by the Government Printing Office.

STATE OF THE ART IN RECREATION FOR HANDICAPPED INDIVIDUALS

Several organized efforts to assess the state of the art in recreation for handicapped persons have been conducted during the last decade. For example:

- The American Alliance for Health, Physical Education and Recreation (AAHPER) sponsored a national conference on "Programming for the Mentally Retarded" in which the current status of programs, training activities, research, and planning were explored;
- In 1969, the AAHPER, in cooperation with the National Recreation and Park Association, conducted a "Study Conference on Research and Demonstration Needs in Physical Education and Recreation for Handicapped Children" during which strides in personnel preparation, legislation, research and resource development were discussed.

However, the most recent and systematic attempt to assess the state of the art has been done by AAHPER under a grant from the Bureau of Education for the Handicapped in HEW. This project, "Physical Education and Recreation for the Handicapped: Information and Research Utilization Center (IRUC)," was initially funded for three years to ". . . collect, synthesize, and disseminate information and materials about programs and services in physical education and recreation for handicapped persons; and to serve as a research utilization center to assist in making research and research findings available and practical."

The comprehensive project report developed by IRUC contains substantial amounts of information on programs, materials, and people involved in recreation and physical education for handicapped persons. Twenty state of the art papers provide summaries of present and past efforts and current needs relative to personnel preparation, research and demonstration, and services in the field of recreation for disabled persons. Topics covered in the report include "mainstreaming," perceptual/psychomotor functioning and professional preparation. Handicapped groups discussed in the report include persons who are mentally retarded, multiply and severely handicapped, orthopedically disabled, visually handicapped, asthmatic, epileptic, diabetic, and hearing impaired. The report encompasses recreation in residential facilities and community recreational agencies. It also describes such approaches as creative arts, diagnostic-prescriptive teaching, play apparatus, and camping.

This report demonstrates the degree of activity and innovation which is taking place in the field; there are many innovative programs in the country. Many of these programs, however, are benefiting only a small percentage of handicapped individuals. Increased dissemination of information regarding model programs is necessary to expand services to larger numbers of disabled persons. More scientific studies are also required to identify those techniques which are most valuable in the provision of services to specific groups of handicapped individuals.

Residential Facilities

As previously indicated, recreation services for handicapped persons started in residential facilities. In the past few years, recreation has increasingly been part of treatment services in hospitals and institutions. The Joint Commission on Accreditation of Hospitals has recognized the value of these services by requiring recreation in residential facilities for mentally retarded persons, psychiatric facilities, community-based programs for mentally retarded persons, and drug abuse treatment centers. As mentioned previously, recent litigation has also established that recreation programs should be a component of any balanced institutional treatment plan for mentally retarded and mentally ill individuals.

Dr. Gerald O'Morrow surveyed a sample of recreation programs in residential facilities and compared results with other studies reported in the literature. He found:

- An acceptance by staff of recreation as a part of the overall treatment program in residential facilities;
- A substantial increase in the provision of recreation services in residential facilities since 1958;
- A greater emphasis on recreation in public than in private facilities;
- A need to validate the specific benefits of recreation; and
- A need for better preparation of recreation personnel.

In concluding his report, O'Morrow stated that the most significant need in recreation services for handicapped individuals is empirical research which scientifically describes the direct relationship of recreation to the rehabilitation process.

Community-Based Programs

Several studies document the growth of community-based recreation services. A 1964 study, sponsored by the National Recreation Association and the National Association for Retarded Citizens, surveyed 2,000 community recreation departments to determine the scope of services provided to physically handicapped and mentally retarded individuals. Of the total surveyed, 427 agencies were found to provide programs or facilities for disabled persons. However, when contacted for follow-up, 139 communities indicated that they served mentally retarded persons in separate facilities and 164 communities served physically handicapped individuals in segregated programs.

In 1967, a survey of 166 major cities throughout the country was done to determine their involvement in recreation programs for mentally retarded persons. Major findings included:

> (1) 55 percent of respondents indicated some type of program for mentally retarded persons; (2) 45 percent employed a staff member who directed these programs; (3) eight percent used a consultant to aid in planning these programs, although they did not employ a director on either a paid or volunteer basis; (4) 37 percent offered city-wide or district programs for mentally retarded persons; (5) 28 percent provided special programs in recreation centers; and (6) 25 percent offered special programs for mentally retarded persons on municipal or special playgrounds.

Berryman, Logan, and Lander conducted a major study of recreation programs in large metropolitan areas in 1971 under the auspices of the Children's Bureau in HEW. The survey showed that 88% of agencies serving handicapped individuals provided some recreation services to handicapped children. The study also pointed out the need for additional programs which integrate disabled with non-disabled individuals, and for the elimination of architectural barriers which hinder the participation of handicapped individuals.

Finally in 1971, the Community Council of New York City conducted a study of administrative problems in recreation and parks utilizing a sample of 80 cities with a population of 150,000 or more. Of the 45 cities that responded, a large percentage reported that they offered services to handicapped persons. (Kraus, 1973)

Although these studies indicate that many localities provide programs for handicapped individuals, the extent of the services provided is not known and the numbers of persons actually being served is still unclear. One author in the recreation field made the following comment on the shortcomings of the information available:

> Over all, although a substantial proportion of municipal and county recreation and park departments now serve the disabled, it is clear that only a small proportion of those needing special services actually receive them. It has been estimated, for example, that public recreation and park departments in California provide services for only 3,000 of the state's 130,000 disabled children. Undoubtedly, similar situations prevail elsewhere throughout the country. (Kraus, 1973)

Other Programs

In addition to institutional and community-based programs, many additional services are provided by voluntary health agencies, consumer organizations, private groups, and other agencies. These programs have had dramatic results for many handicapped persons. For example:

- Visually impaired individuals ski cross-country and down-hill, participate in gymnastics, play golf, skin and scuba dive, wrestle, climb mountains, and run in competitions such as the Boston Marathon;
- Amputees, paraplegics, and quadriplegic persons ski, swim, fish, dive, surf, and take part in gymnastics, pool, archery, hockey, weight lifting, football, basketball, golf, table tennis, track and field; and
- Bedfast individuals take part in dramatic productions, work with clay, paint, and attend parties.

Many different groups participate in the provision of recreation and sports activities for handicapped persons. These programs are increasing at local, state, regional, national and international levels. Some groups are highly organized and structured, while others are informal and loosely organized. Some of these programs include:

- Special Olympics provides opportunities for year round physical fitness and sports programs for mentally retarded individuals at local, county, state, regional, national, and international levels;
- National Easter Seal Society for Crippled Children and Adults conducts camping and recreation programs in most states;
- National Wheelchair Athletic Association organizes sporting events for physically disabled persons on state, regional, national, and international levels;

- National Association for Retarded Citizens provides recreation services for retarded individuals through local affiliates;
- United Cerebral Palsy Association organizes recreation opportunities through local associations and for the last several years has sponsored a national bowling tournament; and
- Many other consumer groups are also providing for leisure needs of their members. For example, local chapters of the National Association for Mental Health sponsor community social activity centers for former institutional residents.

No mention has been made of the commercial and private recreation sphere which, to date, has done little to accommodate the needs of handicapped persons. Even though some progress is being made, especially at the local level, on an individual basis, many needs are not being met.

ISSUES IN MEETING RECREATION NEEDS

While much progress has been made by public agencies and many organizations, much work remains to be done before adequate recreation opportunities are readily available to persons with disabilities. Many of the needs which must be met were identified and discussed at the National Forum on Recreation and Leisure Needs of Handicapped Persons in 1974. Additional problems, priorities, and concerns have been presented in the IRUC Final Report: *Physical Education and Recreation for Impaired, Disabled, and Handicapped Individuals . . . Past, Present, and Future.* (This report is available from AAHPER.) Additional issues have been periodically discussed in publications such as the *Journal of Physical Education and Recreation, Therapeutic Recreation Journal, Therapeutic Recreation Annual,* and *Trends.*

The issues which still must be addressed, in order to meet the needs of disabled persons, include the following:

Continuum of Services

A major debate in the recreation field revolves around the feasibility and desirability of developing separate facilities and programs that segregate handicapped from non-handicapped persons. Generally, the goal of all services to handicapped individuals is to enable each person to function as independently as possible in the least restrictive environment. This goal should apply equally to recreation services for handicapped persons. Although some disabled persons, because of the severity or complexity of their handicapping condition, may need separate and/or sheltered recreation programs, the overall objective should be to increase integrated recreation opportunities for the majority of handicapped individuals. In order to accommodate the needs of all handicapped persons, a continuum of services should be developed which allows for movement from more to less sheltered recreation programs.

Funding Considerations

One of the most common excuses for not developing recreation services for handicapped individuals is that such services are expensive and that sources of funds are limited. Several factors shed light on this argument. First, the Federal government has increased its interest in and funding of recreation services for handicapped persons; however, many of these programs provide funds almost exclusively for training, research, demonstration, and only to a limited degree for program and facility development. Though some funding does exist (as discussed in the section on Federal Activity), more is needed for development of actual programs. Potential sources of such support include P.L. 94-142 *(Education of All Handicapped Children Act of 1975)* and local revenue sharing. The provision of Federal and other "seed money" to establish pilot programs offers a positive approach to the problem. The impact of the seed money generated by the Kennedy Foundation, mentioned earlier, is a good example of the positive results of this strategy. The willingness to develop services exists in many communities—yet without start-up funds, most programs are "still on the drawing boards."

Ultimately, however, the funding argument ignores the real issue—recreation departments are publicly supported and they should serve *all* citizens of a community. Provision of recreation services for handicapped persons is not only desirable but required. Regardless of the size of the budget, a portion should be spent to make programs accessible to and usable by handicapped persons.

Architectural Barriers

Architectural barriers legislation and its implications for recreation facilities and areas has been discussed. A major reason many handicapped persons do not participate in existing recreation programs is simply that facilities are not physically accessible and barrier-free. Major efforts need to be expended to enforce *all* legislation concerning the elimination of architectural barriers at national, regional, state, and local levels. Existing buildings and facilities must be made accessible and new buildings should incorporate barrier-free designs. More thought must also go into the development of accessible recreation and park facilities. Information regarding accessible and barrier-free recreation programs also needs to be broadly distributed to recreation planners.

Transportation Barriers

It is one problem to make facilities and areas accessible, but another to enable a handicapped person to travel to such programs. Going places is a major part of recreation for most people and until transportation problems for handicapped people are solved, they will be unable to enjoy equal recreation and leisure opportunities.

Communication Barriers

Communication barriers relative to recreation participation also exist. Most recreation opportunities are designed for individuals who can see, reason normally, hear, and speak; many handicapped individuals have disabilities in these areas. Efforts need to be made to adapt communication systems and devices so all people, including those with communication problems, can take part in recreation experiences.

Another type of communication problem also exists. Many community recreation departments assert that their programs have always been open to handicapped people but they just don't take advantage of them. Lack of participation is in many instances a direct result of lack of knowledge. To solve this problem, effective outreach programs must be established to inform disabled persons who are isolated and out-of-touch about the availability of recreation services.

Attitudinal Barriers

Attitudes of the general public toward handicapped people and attitudes of handicapped people toward themselves, others, and toward recreation must be changed. All involved—including program administrators and legislators—must begin to recognize the importance of recreation in the lives of handicapped persons and must be willing to open community recreation opportunities to even the most severely disabled persons.

Manpower Needs

Tremendous strides have been made in the past ten years in providing professional training programs in recreation in general and in therapeutic recreation in particular. Over 500 colleges and universities provide training programs in recreation and parks careers, and close to 100 provide programs in therapeutic recreation. The increase in the number of persons with specific training in recreation for handicapped persons is resulting in service improvement, Manpower problems, however, still need serious attention. Even though numbers of trained personnel are increasing, many sections of the country are still almost without services. Existing training programs are located in population centers and graduates tend to stay in the particular region in which they received training. The result is an overabundance of trained personnel in some areas of the country and serious shortages in others. A wide disparity in salaries also exists from one section of the country to the next. "Underdeveloped areas" tend to pay much lower salaries and because of the lack of trained personnel, professional status is also lower. This continues to deter trained individuals from moving to areas which need their services most.

Employment opportunities for handicapped persons themselves in the recreation, park, and leisure field need special attention and emphasis. Since disabled individuals can and should participate in recreation activities, they should also have opportunities to be employed in these areas. Some efforts are currently underway to promote these opportunities. In 1971, the Rehabilitation Services Administration in HEW funded the National Recreation and Park Association (NRPA) to explore the potential of employment

for handicapped persons in the leisure services field. Currently the Bureau of Education for the Handicapped is funding NRPA to develop career education materials for handicapped persons in the areas of recreation, tourism, and hospitality.

Research Needs

Implications of research in recreation services to handicapped people has been touched upon in other sections of this paper. The entire final report of the Information and Research Utilization Center is devoted to research needs in this area. The Bureau of Education for the Handicapped (BEH) has taken the lead in stimulating such efforts and as reported by IRUC, substantial progress has resulted. Yet, the total amount of money expended by BEH in research for physical education and recreation is a small amount compared to research in other areas of special education and in comparison with identified needs. If recreation and leisure are to be important facets of the lives of handicapped persons, more support from Federal agencies is necessary. Other agencies—public and private—need to be concerned with research efforts in recreation. The Rehabilitation Services Administration in HEW has funded several research projects over the years, but no organized investigation of the role of recreation in rehabilitation has taken place.

Leisure Education

In 1975, the National Recreation and Park Association received a three year grant from the Lilly Endowment to develop a leisure education model to be incorporated into public school systems throughout grades kindergarten through twelve. The basic philosophy of the leisure education movement is that people will continue to have increased leisure and that many are unprepared to make the most profitable use of this time. Many citizens do not really understand the role that leisure can play in making life meaningful. In fact many individuals continue to value work and vocational preparation as much more important pursuits. The primary objective of leisure education is to prepare people for leisure just as they are currently prepared for vocations.

In 1975, the Bureau of Education for the Handicapped funded the Leisure Information Service, a Washington based private consulting corporation, in conjunction with the National Recreation and Park Association, to explore the development of leisure education for handicapped children. At the present time, this project has developed a basic rationale statement that is being studied by professionals from many different fields. The rationale statement says:

> Many handicapped persons, especially those with severe disabilities, can be expected to have disproportionately more leisure time than others because they have more limited employment opportunities. Even those able to achieve a satisfactory level of leisure competence may find themselves confronted with many unfilled hours because they cannot reach community resources or because they may lack the social skills which accompany many activities and are essential in forming and sustaining friendships and dating relationships.

The problem of enforced leisure is underscored by statistics provided in a 1975 report of the National Advisory Committee on the Handicapped:

> Only 21 percent of the handicapped children leaving schools in the next four years will be fully employed or go on to college. Another 40 percent will be underemployed, and 26 percent will be unemployed. An additional 10 percent will require at least a partially sheltered setting and family, and three percent will probably be almost totally dependent.

In light of this profile, there can be little doubt that handicapped children and youth require alternatives to vocational education. They must have opportunities to learn how to use leisure time in a way which brings personal rewards and which enables them to contribute to the life of their community. It is the opinion of this writer that the leisure education movement has tremendous potential for enhancing the lives of people with disabilities and should be fully explored and used as a means of improving the total quality of their lives.

CONCLUSION

Recreation is a significant and necessary part of the human development of handicapped and non-handicapped individuals. Recreation represents a full range of activities which meet an individual's need to explore his or her full potential. Although too few handicapped persons are being served and many of those who are being served are helped on a segregated basis, recreation programs are being improved.

Voluntary health organizations and special interest groups have helped to expand recreation services for handicapped persons. Recreation professionals have contributed to the expansion of recreation services in hospitals and other institutions and have helped develop community-based recreation programs. Federal legislation which authorizes funds for recreation programs for handicapped children and youth has also promoted the growth of services.

Meeting the needs of handicapped persons requires the integration of recreation services, where possible, and increasing the funding of recreation services (including training, research, demonstration, as well as program and facility development).

Architectural, transportation and communication accessibility is a key element in assuring that existing and future recreation programs are fully utilized. Recreation and leisure activities offer opportunities for renewal of self and for the improvement of the quality of life.

BIBLIOGRAPHY

Berryman, Doris, et al., *Serving Disabled Children: Guidelines for Recreation Agencies,* New York University, School of Education, 1971.

Frye, Virginia and Martha Peters, *Therapeutic Recreation: It's Theory, Philosophy and Practice,* Harrisburg, Stackpole Books, 1972.

Gray, David and Sy Greben, "Future Perspectives," *Parks and Recreation,* Volume IX, Number 6, July, 1974.

Kraus, Richard, *Therapeutic Recreation Service, Principles and Practices*, Philadelphia: W.B. Sanders Co., 1973.

Park, David C., Ed., "Trends for the Handicapped," *Trends,* 3rd Quarter, 1974, National Recreation and Park Association, Washington, D.C., 1974.

O'Morrow, Gerald, *Therapeutic Recreation: A Helping Profession,* Reston, Virginia, Reston Publishers, 1976.

_____ *Recreation and Handicapped People,* The President's Committee on Employment of the Handicapped, Washington, D.C. 1974.

_____ *Barrier Free Site Design,* U.S. Department of Housing and Urban Development, Washington, D.C., 1975.

_____ *Leisure Education for Handicapped Children and Youth: A Rationale,* Leisure Information Service, Washington, D.C., 1976.

_____ *Final Report,* Information and Research Utilization Center, American Association for Health, Physical Education and Recreation, Washington, D.C., 1975.

PARTICIPATION IN CULTURAL ACTIVITIES

Awareness Paper based on a Paper by

Virginia Cassiano
National Center for Urban Ethnic Affairs
Washington, D.C.

TABLE OF CONTENTS

	Page
Introduction	135
Barriers to Participation	136
Architectural and Design	136
Transportation	137
Communication	137
Special Problems	138
Arts Education	139
Rationale	139
Education in the Arts	139
Arts in Basic Education	140
Specialized Arts Education and Enrichment	140
Model Curriculum	141
Model Programs	141
Training in Arts Education	142
Arts Therapy	142
Legal Activity	143
Architectural Barriers	143
Rights of Handicapped Persons	143
Education	144
Developmentally Disabled	144
Conclusion	144
Bibliography	145

ACKNOWLEDGMENT

The White House Conference on Handicapped Individuals wishes to thank, for his significant contribution to this paper:

Mr. James A. Sjolund
The National Committee,
Arts for the Handicapped
Washington, D.C.

INTRODUCTION

A quote from a recent speech given by Dr. Virginia Trotter, Assistant Secretary for Education, Department of Health, Education, and Welfare (HEW), highlights the importance of cultural and artistic experiences in *all* of our lives:

> I am convinced that the quality of our individual lives and the quality of our society are directly related to the quality of our artistic lives. If we really care about the dignity of the individual–about his potential for self-fulfillment–then we must have a deep sense of a place for the arts in our education, in special education, and in our individual lives. We need the arts if we are to be whole human beings–fully alive and vital–in control of ourselves and our environment.

The phrasing of a recent resolution passed by the National Council on the Arts (the policy-making body of the National Endowment for the Arts) reflects the affirmative posture which should be taken by society in general to foster equal access to cultural opportunities. The resolution states in part, "Arts are a right not a privilege, and no citizen should be deprived of the beauty and insight into human experience that only the arts can impart . . . ." The sentiment conveyed by the resolution is a step toward recognizing the need to make artistic and cultural experiences more accessible and available to handicapped persons.

These actions are recent, however, and must be viewed against a historical background of ignorance and inaction. The cultural development of handicapped individuals has never been a high priority with legislators, arts administrators, or social service agencies in general. Handicapped persons, at best, have been regarded as passive observers of the arts–an attitude which has denied their need for expressive, creative experiences. By continuing to view these citizens as existing on the periphery of artistic expression, we reinforce their isolation and make it impossible for such persons to integrate cultural activities into their everyday lives.

In analyzing the opportunities for handicapped persons in the arts, there are four major areas of activity which should be considered:

1. *Creative expression*–Handicapped persons can and should be represented in the artistic community as actors, dancers, artists, writers, musicians, sculptors, singers, etc.;
2. *Creative appreciation*–It should be possible for handicapped persons to appreciate and experience all forms of art (e.g. museums, galleries, theaters, etc.);
3. *Instruction in creative expression*–Art education should be included as part of the curriculum for all handicapped individuals and specialized art education programs should be made available, when necessary, to such persons; and
4. *Therapy through creative expression*–Within the specialized treatment programs for mentally and physically handicapped persons, art therapy should be included as a tool in the rehabilitation process.

Concentration on each of these four areas is important if handicapped persons are to participate meaningfully in all phases of creative endeavor.

Though specialized cultural programs for handicapped individuals are still woefully inadequate, some model programs do exist around the country. They include:

- *Mary Biddle Duke Gallery, North Carolina Museum of Art*–Founded in 1964, this was one of the first "tactile" art exhibitions which made it possible for visually impaired persons to experience art through touch;
- *Eugene O'Neill Memorial Theater Center, Waterford, Connecticut*–The Center supports three programs for deaf persons. The National Theater for the Deaf is a professional performing arts company combining the visual language of deaf persons and the spoken word. The dialogue is synchronized with the graceful and expressive gestures of sign language. This new art form is supported by an audience which is more than four-fifths hearing persons. The Little Theater of the Deaf, which is the second component, also uses combinations of sign language, mime, and spoken word to produce plays for young children. The productions have generated a number of provocative plays which have expanded the artistic experiences of handicapped and non-handicapped youngsters as well. The Professional Dramatic Training Center for the

Deaf is the third element in the Center and is the largest program of its kind in the Western world. Through Connecticut College, the Center is able to grant a master's degree in theater for educators of deaf individuals;

- *Little Theater for the Blind and Sighted, Main Line Center of Arts, Haverford, Pennsylvania*–The Little Theater produces original plays with interchangeable parts for both blind and sighted actors; and
- *Tactile Gallery, Wadsworth Antheneum, Hartford, Connecticut*–Sculptor Doris Chase makes it possible for visually impaired persons to feel the spatial, textural and other dynamic components of sculpture through touch. Artists at the Gallery work with handicapped persons through dance and other art mediums to enhance their perception of creative expression and to sharpen their receptiveness to the "messages" being communicated by works of art.

These examples concretely reflect a vision of handicapped persons as full participants in cultural activities, not just as bystanders. People with disabilities, like other individuals, must have the opportunity to make the arts a vital and important part of their existence. Involvement in the arts assists disabled persons in developing creative outlets and can help individuals who need to overcome problems of isolation and negative self-concept. Their isolation can be reduced through aggressive efforts to eliminate physical and other barriers to their participation in cultural activities in their communities. A more positive self-image can be reinforced by developing programs which elicit creative expression in a variety of mediums.

To the extent possible, cultural development of handicapped persons should take place in integrated settings. Such programs, however, should be sensitive to the special needs of such persons and should include the support services necessary to assure full participation and/or appreciation.

The expansion of cultural and artistic experiences to *all* handicapped individuals must be a shared responsibility. Administrators, legislators, therapists, educators, artists, and handicapped persons who have succeeded in breaking down some of the barriers in the art world, must all participate in increasing such opportunities. Only in this way can we guarantee that the potential creative contribution which handicapped persons can make to the cultural life of our society will not continue to be overlooked.

BARRIERS TO PARTICIPATION

Architectural and Design

Architectural barriers pose one of the major obstacles to handicapped persons seeking access to cultural events, displays, exhibitions, etc. Poorly planned facilities make it impossible for many handicapped persons to gain entry to cultural activities. The effect is clear discrimination against a segment of the potential audience. In theaters and movie houses, those persons in wheelchairs are frequently confronted by narrow doorways; steps without ramps; and inaccessible toilet facilities, telephones and drinking fountains. Theater managers often complain that it is too inconvenient or expensive to utilize removable seats for those in wheelchairs. (They are also loathe to unseat a non-handicapped orchestra-paying customer.) Such discrimination reinforces the isolation of handicapped citizens and effectively excludes many from full participation.

In addition to theaters, museums also have reneged on their responsibilities to disabled persons. Paintings and their titles are often hung too high to view effectively from a wheelchair. Thick rugs or gravel paths are unmanageable for persons who are in wheelchairs.

Arts administrators should realize that such physical barriers exclude potential paying customers and, in addition, they eliminate a source of potential support for expanded cultural events. Fortunately, some programs exist which show how easy it is to overcome architectural barriers with a bit of imagination.

The Brooklyn Children's Museum in New York City proves that barrier-free architecture can be aesthetically pleasing and unobtrusive. All the exhibits are equally accessible to the handicapped and the non-handicapped child. Graphic symbols are utilized for deaf children. Handrails are the tactile mapping system used for the sighted as well as the non-sighted child. The multi-level museum is easily negotiated by those in wheelchairs.

Tactile galleries eliminate glass cases and roped barricades, and make it possible to experience

art through touch and other senses. The most successful of these galleries are those which appeal to non-handicapped as well as handicapped persons. Through integrated programs, they are able to expand the senses of *all* who participate.

Several innovative galleries exist around the country. Some examples include:

- the *Krannert Art Museum, Champaign, Illinois*—A barrier-free facility which includes an emergency fire ramp, and titles and explanations in Braille;
- the *Nevil Gallery for the Blind and Sighted, Philadelphia, Pennsylvania*—A gallery for visually impaired persons which has handrails, Braille labelling, and playable musical instruments from several nations; and
- the *Semetic Museum, Harvard University*—A museum with a collection of ancient art objects from the Near East which can be touched and experienced, and interpreters for deaf persons are available to act as guides.

Transportation

Even if the architectural barriers to accessibility are removed, handicapped individuals will still be hampered in their ability to secure transportation to cultural events. Most buses and trains cannot accommodate physically handicapped persons in wheelchairs, and access to these vehicles is extremely difficult for most persons with mobility problems. Some taxis are built to be utilized by wheelchair riders, but the costs to low-income handicapped persons are often prohibitive. For many persons who are mentally disabled, public transportation systems are confusing and difficult to negotiate without training and/or assistance.

In addition to problems of transportation, other logistical obstacles preclude access to cultural events. Sidewalks without curb cuts, underground garages without elevators, and remote parking lots all pose hurdles for handicapped persons to overcome.

Some attempts have been made, however, to provide accessible transportation which is free or discounted. For example, Hempstead, New York supports music, dance and art programs for physically and mentally handicapped children. Free bus transportation is available for all participants who wish to use it.

Another way of approaching the problem is to establish outreach projects which bring the arts to the people, rather than *vice versa*. In Atlanta, Georgia, the High Museum of Art created the Georgia Art Bus which carries original art-works to schools in farm areas and small towns. Although the program is not designed specifically for handicapped persons, they do benefit substantially from the Art Bus and other similar programs around the country.

The problem of access is particularly important to mentally disabled persons who reside in residential institutions. Since many of these individuals rarely have the opportunity to go "off grounds," there is a distinct need to bring cultural experiences to them—either through something like the Art Bus or other innovative mechanisms which expand the access of institutionalized persons to the mainstream of cultural activities. Such exposure is especially important for those persons who are expected to eventually return to the community since it enhances their contact with the world around them and aids in their transition back to everyday life.

Communication

A major problem in increasing access to the arts, is the gap in communication which exists between non-handicapped and handicapped individuals. This gap is aggravated by the negative image of handicapped persons which is perpetuated by popular myths, the media, ignorance, etc. Because most non-handicapped persons have had little or no contact with disabled individuals, the stereotype of handicapped people as "different" often goes unquestioned.

It is only through increased interaction with handicapped citizens that an awareness of the qualities which all of us share in common can be developed. This understanding is crucial if efforts to include disabled persons in the cultural life of the society are to be successful.

Family Communications and the Bureau of Education for the Handicapped (HEW) have sought to alter this image. In 1971, these two organizations entered into a contract to produce programs for *Mister Rogers' Neighborhood*, an educational television series designed to increase a child's understanding of the value of each person. In one *Mister Rogers* program, an actor from the National Theater of the Deaf shows how initial fearful reactions to a handicap can be changed

to acceptance once communication is established. Other programs stress the idea that we are all more alike than different. This type of sensitive broadcasting is necessary to alter stereotypes and communicate information about handicaps to both non-handicapped and handicapped children and adults.

In addition to enhancing communication for the purpose of changing attitudes, there is also a need to address the specific communication difficulties experienced by visually and hearing-impaired individuals. For instance, many radio stations are scheduling shows of particular interest to blind individuals. Captioned TV enhances communication of deaf persons in the audience. News in sign language is also becoming more prevalent. Programming of cultural events in a mode suitable for those with communication problems should be increased.

Another communication barrier is the lack of centralized services which compile the latest information regarding accessible arts programs. Educational Facilities Laboratories (EFL) in New York, has begun to fill this void. A report from EFL and the National Endowment for the Arts (NEA), "Arts and the Handicapped: An Issue of Access," is the first document which compiles relevant information on accessible arts programs including facility design, legal issues, museums, educational and community arts programs, nature centers, trails and fragrance gardens. Under a separate NEA contract, EFL has started a national information service on the arts and handicapped persons. As part of this service, EFL will explore model facilities and programs; seek out relevant legislation; identify technical and design consultants; and provide responses to specific inquiries and requests.

Special Problems

Architectural, transportation, and communication barriers affect a broad range of handicapped persons, but there are also groups within the handicapped population which experience special difficulties. Additional barriers such as poverty, language, and isolation compound the problems of access to cultural activities for many disabled persons.

Because a large number of handicapped persons—especially the more severely disabled—are forced to exist on very low incomes, their ability to participate in the arts is substantially hampered. They cannot afford to pay for either "the privilege" of enjoying the arts or the materials and/or training needed to express themselves creatively. Unless the arts community—and other agencies—are willing to provide funds to assist the efforts of such persons, their artistic contributions will be lost and their cultural experiences severely limited.

Handicapped persons who are minority group members and persons who have only a limited facility in English also have difficulties in gaining access to the cultural life of the community. Language barriers make it hard for persons with limited English ability to gain information about cultural and creative opportunities. The isolation forced on many minority group members alienates them from the general cultural community. Couple these disabilities with the other disadvantages faced by handicapped persons and it is clear that these groups suffer double discrimination.

In rural areas where arts resources are scarce, the problems of accessibility are especially difficult. Sheer distances, in combination with the transportation barriers mentioned earlier, make it extremely difficult for handicapped individuals in outlying communities to acquire training in the arts, to make use of art therapy progrms, or to participate in creative activities. This problem is also experienced by mentally disabled persons who live in remote institutions.

Certain programs are currently addressing some of the special problems discussed above. For example, the Family Learning Program in Santa Fe Springs, California, is a model arts program which is striving to overcome the isolation of persons in the Mexican American community. Specifically geared to children with learning and perceptual problems, the program operates in backyards, community centers, schools and churches. The staff combine education, therapy and the creative arts as they teach mothers how to build perceptual toys, playgrounds and tools from free or inexpensive materials. At the same time, parents are also taught how to use these techniques to reinforce perception, language skills and motor coordination. Sensory playgrounds and shape mazes built by the parents stimulate their creativity, and the perceptual and aesthetic awareness of their children.

This model program could be used successfully in other geographic locations and with various ethnic or minority groups. Family involvement is the key to making the program work.

ARTS EDUCATION

Rationale

Handicapped persons as a result of physical, programmatic, and other barriers have been denied full access to the arts and, therefore, have been deprived of the beauty which art can bring to their lives. In a recent study of accessibility to arts programs by the National Committee, Arts for the Handicapped,* it was found that handicapped individuals are systematically excluded from arts education programs. In one State, for example, only 19% of all handicapped children had access to arts programs in the schools compared to 85% of their non-handicapped peers. Levels of services for adults show a similar disparity.

Jean Kennedy Smith, National Chairperson of the Alliance for Arts Education, commented on this discrimination in a recent statement:

> More and more we are learning to understand that for every artist who has painted a picture, composed music, or written poetry, and for all the teachers who have educated students in the arts, and for all of us who have enjoyed the genius of artists, there have been others who have been excluded from even the chance to see the portrait, hear the song, or read the verse. They have been excluded because we have branded them "Handicapped" or "Retarded" and therefore have considered them "Unappreciative."
>
> . . . . Only when every child in our society can be assured the opportunity to share in an appreciation of the arts, can all of us claim a share in the wonder of the talent, the creativity, and the joy of every child.

In an article entitled "A Rationale for Arts in Education," co-authors Kathryn Bloom and Jane Remer list specific ways that the arts can contribute to the general education of every handicapped child. They suggest that arts education can:

1. Provide a medium for personal expression;
2. Focus attention and energy on personal observation and self-awareness;
3. Promote a deeper understanding and acceptance of the similarities and differences among races, religions, and cultural traditions;
4. Supplement basic learning skills;
5. Enhance children's understanding of their own cultural heritage in a broad historical context;
6. Provide opportunities for students to test various career options in the arts;
7. Provide alternative learning approaches for students with learning disabilities;
8. Encourage positive attitudes toward learning in general; and
9. Develop useful tools for everyday living.

In summary, comprehensive arts education can be a vehicle for accelerating the movement of handicapped persons into the "mainstream" of society.

Education in the Arts

The first component of a comprehensive arts education program is instruction in specific arts disciplines such as dance/movement, music, painting, sculpture, film, drama, and the many traditional and newly emerging art forms. A definition of the "arts" for purposes of Federal funding is contained in the legislation of the National Endowment of the Arts and the regulations for P.L. 93-380, *The Education Amendments of 1974,* in the section regarding arts education for handicapped individuals. This latter definition is broad and includes:

> . . . music, dance, drama, folk art, creative writing, architecture and allied fields, visual arts (including painting, sculpture, photography, graphic arts, and craft arts), industrial design, costume and fashion design, motion pictures, television, radio, tape and sound recording, the arts related to the presentation, performance execution, and exhibition of those arts, and the study

*The National Committee, Arts for the Handicapped is a private non-profit corporation consisting of representatives of major national professional organizations including arts education, general education and organizations serving handicapped persons. The Committee maintains contact with over two million professionals throughout the United States who are engaged in providing educational programs for school age children and for adults.

and application of the arts to the human environment.

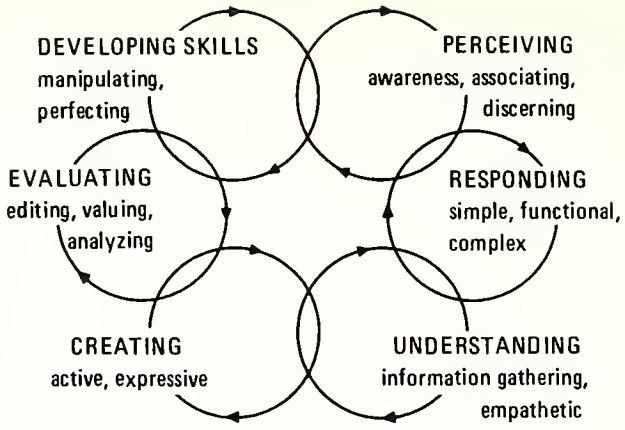
As mentioned previously, education in the arts makes it possible for handicapped persons to expand their world and to avail themselves of experiences previously closed to them. As increasing numbers of handicapped persons enter the various creative arenas, the stereotype of the handicapped person as "inferior" should be diminished. Such exposure reinforces the common creative potential among handicapped and non-handicapped individuals alike.

Educators of handicapped persons assert that art is a crucial component in any curriculum which is aimed at the development of more "normalized" life styles. Educational programs should meet the general needs of handicapped students through regular instruction in the various specific art forms; and the needs of gifted and talented handicapped students through the provision of in-depth study and/or performance opportunities. Such programs form the basis of traditional approaches to arts education.

Arts in Basic Education

A second component of a comprehensive arts program can be termed "Arts in Education" or "Arts in Basic Education." These phrases imply an integration of the arts into the basic curiculum. In this way, arts instruction can enhance the teaching of basic learning skills while stimulating the aesthetic and perceptual development of the child. Those faculties which are called upon in the process of art education include: perceiving, responding, understanding, creating, evaluating, and developing manipulative skills. These skills or learning concepts are interdependent, interrelated, non-sequential and intertwined. They are interdependent because one cannot function without the other, interrelated because each provides experience that nurtures the others, nonsequential because one does not necessarily precede the other, and they are intertwined because each requires deliberate action and attention.*

The abilities utilized in the art education process can be depicted as:†



Persons who develop these skills become:

1. EXPLORERS: searching for and discovering significant new experiences;
2. APPRAISERS: formulating value judgments about the world which they explore;
3. TRANSFORMERS AND COMMUNICATORS: dealing in revelations and striving to transform and relate that which they perceive in the world around them; and
4. PERFECTORS: exercising their imaginations and polishing their techniques to give exactness, clarity and impact to their insights.

In summary, when arts instruction is utilized in the basic education process, the general learning process is qualitatively enhanced and qualitatively heightened. This component, which infuses the arts into general learning, is especially important for educational programs serving mentally handicapped individuals.

Specialized Arts Education and Enrichment

A third major component of a comprehensive arts education program is "Specialized Arts Education and Enrichment" for handicapped children. This entails exposing the student to specialized "artistic awareness" experiences. Such activities may be designed for handicapped students and often include cultural programs in the schools or trips outside of the school for enrichment purposes. Special programs are designed to supplement but not to supplant the regular school arts programs. To provide these experiences, many valuable community resources can be utilized which will broaden the handicapped child's knowledge of the cultural activities which exist in his or her environment.

*These areas of skill development are spelled out in a publication of the Pennsylvania Department of Education entitled, "The Arts Process in Education."
†*Ibid.*

Model Curriculum

Acceptance of the notion that the arts have a central place in the general education curriculum has led to an increased interest in the development of a curriculum for the arts. A three dimensional model curriculum specially designed for handicapped youngsters has been developed by Dr. Richard Graham of the University of Georgia, cooperatively with the Clarke County, Georgia, School district. It is being tested and will be distributed nationally by the National Committee, Arts for the Handicapped, in the near future. On one dimension, the curriculum has five levels:

1. Awareness of artistic behaviors;
2. Imitation of artistic behaviors;
3. Self-initiation of artistic behaviors;
4. Skill development; and
5. Ability to make critical judgments.

A second dimension considers conceptual areas common to all art forms:

1. Rhythm;
2. Laterality and direction;
3. Self vs. Environment and others;
4. Sequencing and time; and
5. Same/different.

The third dimension of the curricular model is represented by each of the arts: music, visual arts, drama and dance/movement. School and community resources are interwoven in the model, which is behaviorally designed. The curriculum guide provides suggestions for teacher and learner activities to accomplish the behavioral objectives.

The importance of the model is that it brings together, perhaps for the first time, all components of a comprehensive arts in education program specially designed for handicapped children: These components include:

1. Awareness (enrichment);
2. Skill building (education in the arts); and
3. Development of critical judgment capabilities as well as general learning improvement (arts in education).

Model Programs

The Exceptional Children's Foundation Art Center in Los Angeles, California teaches the arts to severely mentally retarded students. The skills taught enable the students to produce ceramic sculpture, painting, and collages as well as other art works. Besides gaining a sense of self-worth, some of these students have been able to earn an income as professional artists. Though the program is therapeutic, its primary focus is on the development of artistic ability in the student. Another California-based program is located at the College of Arts and Crafts in Oakland. Their studio-classroom facility has special accommodations for persons with paraplegia. Some of the design classes have done considerable work in the area of developing special tools for handicapped children.

The Sacramento Ballet transforms a performance into a learning experience for blind persons. Special electronic earphone equipment is provided while a commentator transmits the visual picture of the ballet as the audience listens to the musical accompaniment. Following the performance, the blind audience is invited backstage to meet the dancers and learn about the costumes and scenery.

In Briston, Pennsylvania, the school system sponsors a summer camp for emotionally disturbed and mentally retarded children between the ages of five and fourteen. The activities include creative dramatics, puppet theater, dance, improvisation, crafts, story-telling and film. While students learn about the arts they also learn to concentrate and channel their energies constructively. Capturing a child's attention is the first goal. The arts are often the tool used successfully in achieving this goal, which is followed by the teaching of other subjects. This is especially useful in teaching children with learning disabilities.

Gallaudet College in Washington, D.C., and the National Technical Institute for the Deaf (NTID) in Rochester, New York, provide an arts education for hearing impaired students from around the country. At Gallaudet deaf students can major in drama or in the visual arts. While no masters or graduate degrees are offered in the arts, the school's placement service helps find an appropriate postgraduate program at another college.

NTID, the nation's only postsecondary technical school for deaf persons, provides an associate arts degree and the opportunity to major in photography, printing, drama, fine arts, and crafts. Courses are available in advertising, graphic arts, display and graphics, furniture, and stage design. A new experimental theater, which has

been designed especially for deaf persons has special lights in the first 200 seats for the audience to follow the script while watching a play. A closed-circuit television system replaces the traditional headset linking the stage manager to lighting control, the orchestra and stagehands.

Training in Arts Education

There is a nationwide need to assist persons who are charged with designing, supervising and offering arts programs for handicapped students. The following steps should be taken to assure that such persons have the resources necessary to enable them to provide quality arts education:

1. Collection and assessment of data on existing training programs;
2. Collection and assessment of data regarding competencies necessary for teachers of Arts in Education;
3. Teacher and specialist participation in an observation of actual learning programs involving target students in arts experiences;
4. Cooperative action with institutions preparing teachers for careers in special education;
5. Dissemination of findings through established channels;
6. Development of a comprehensive national plan for infusion of arts experiences into programs for handicapped students; and
7. Preparation of guidelines for training and for evaluation of training programs in the arts for handicapped persons.

The National Committee, Arts for the Handicapped is developing a training model which addresses these issues.

ARTS THERAPY

The notion that artistic expression can be utilized to accomplish therapeutic ends (with the implication of curing or healing) became acceptable after World War II when such techniques were utilized in the rehabilitation of disabled veterans and polio victims. From adult rehabilitation centers, music, dance, art, occupational and physical therapy gradually appeared in special and regular education programs.

As more is understood about the interaction between learning and development, as well as creative expression, the boundaries between education in the arts, and arts therapy become somewhat fuzzy—both contribute to the growth and well-being of the handicapped person. For purposes of this paper, however, we will distinguish arts education and arts therapy by the general goal which characterizes each. The major objective in arts education is to develop competencies in artistic expression, whereas the overarching goal in arts therapy is to improve the level of intellectual or physical functioning of the handicapped person.

Recent research highlights examples of successful therapeutic and psychotherapeutic arts programs, and reinforces the need for broadening the scope of arts therapy programs in schools and institutions throughout the United States.

A study conducted in 1964 showed that mentally retarded children made significant gains in classroom behavior and speech and language skills through arts programs; another study found that creative drama can free a deaf child from the failure frequently associated with written words. Irwin and McWilliams, in a 1974 study, found that drama activities used with cleft palate children resulted in *each child* showing significant improvement in verbal as well as social skills. Use of music activities with disabled children can improve speech, help to regain use of limbs, improve rhythmic sense, and serve to relax muscles. Still another researcher found that blind children score significantly higher than sighted subjects on tests of musical ability. Significant gains were noted when art lessons were provided for emotionally disturbed children, and similar gains in reading skills by emotionally disturbed learners were documented after arts programs were introduced.

Frances Mertz, in an article titled "Art Therapy with a Retarded Schizophrenic Adolescent," states that:

> Art therapy is useful with the retarded schizophrenic in that the subject can become involved emotionally in his art work as a step in becoming more involved with life . . . [The adolescent subjects were] characterized as apathetic, nervous, isolated, and unable to deal with stress. Papier mache, metal and wood sculpture, clay and potter's wheel were selected and utilized as the appropriate media for the subject to express his feelings during various stages of therapy. Learning to concentrate and gaining

confidence in conversation resulted in the subject becoming more aware of his emotions and channeling them into socially acceptable work.

Jess Averback reported on the use of the "Chinese jump rope" (a continuous woven elastic material) in music therapy at the Pacific State Hospital (Pomona, California) with institutionalized profoundly and moderately retarded, cerebral palsied, non-ambulatory and psychiatrically ill persons. The application of the new technique led to improvement in mobility, motility, communication, coordination, posture, dexterity, social interactions and also resulted in a reduction of hypoactive and hyperactive symptoms.

Dance therapy was included as part of the treatment program at St. Elizabeth's Hospital in Washington, D.C., in the early 1940's. The technique has spread throughout the country and there are now over five hundred dance therapists in the American Dance Therapy Association. Such treatment has been successful with mentally handicapped individuals, as well as blind, deaf and other physically handicapped persons. At the Center for Autistic Children in Philadelphia, dance therapy is used as a key to discovering the self-image of the child through his body image. After sessions with a therapist, tense or bound movements can develop into more relaxed patterns signifying trust which could be the beginning of communications with a non-verbal child.

Persons who are visually handicapped can minimize their movement inhibitions by experiencing their potential through dance. Spatial concepts can be clarified for the individual as he or she explores the immediate environment through dance.

Choreographer Fanny Yeh, who is deaf, believes that the awareness deaf persons have for body movement makes them particularly sensitive to the impact of dance therapy. Dance therapy helps overcome the barrier of isolation by making it possible to communicate ideas and emotions through movement. Deaf individuals, with an acute awareness of vibrations and visual signals, can participate with hearing dancers in learning and performing. Dance therapy can often instill a sense of self-confidence in ways no conventional therapy can.

A sculpture class for blind and sighted persons at the Main Line Center for the Arts in Haverford, Pennsylvania, provides the opportunity for handicapped persons to express their creativity and to learn a craft together. Because blindness can produce a greater sensitivity to form, latent talents among blind individuals can be encouraged.

Severely retarded people perform and read music at the Arkansas Children's Colony in Conway. A simplified musical coordinating device has been invented which enables the students to perform as well as those students in many junior high schools. The device consists of an illuminated box on metal stands. Squares on a sheet of paper illuminate signals for the students who read music.

These examples demonstrate that not only "survival skills" but also artistic skills contribute to the rehabilitative process. To be "mainstreamed" into society, one should be prepared to participate in many areas of the society. Arts therapy can provide an avenue through which handicapped persons can achieve the goal of self-fulfillment.

LEGAL ACTIVITY

Architectural Barriers

Some recent Federal activity has resulted in legislation directed at the removal of the physical and design barriers which prevent access to artistic and cultural activities. A major step was the passage of the *Architectural Barriers Act of 1968* (Public Law 90-480) which requires that any new public building or facility funded in whole or in part from Federal monies must be fully accessible to all handicapped persons. Although enforcement of this law has been inadequate to date, the Architectural and Transportation Barriers Compliance Board was established in 1973 to enforce the 1968 Act. The Board has the authority to withhold funds from any organization failing to comply with the law's intent. With this incentive, it is possible that many of the currently-existing physical barriers to cultural activities will be removed.

Rights of Handicapped Persons

Another major statute affects discrimination against handicapped persons generally. Section 504 of the 1973 Rehabilitation Act (Public Law 93-112) states that:

> . . . no otherwise qualified handicapped individual in the the United States . . . shall, solely by reason of his handicap, be excluded from participating in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal assistance.

Regulations to guide the enforcement of the Act have been compiled by the Office of Civil Rights (under the authority of a Presidential Executive Order) and will have an impact on a broad range of Federally subsidized programs. The arts are affected in this case through monies allocated by many agencies including the National Endowment for the Arts. The specific responsibility of the Arts Endowment in implementing these regulations is not yet clear. For example, should Federal funds support a symphony located in an inaccessible theater? Should funds be earmarked for special support services for handicapped individuals such as interpreters for deaf persons?

The full effect of this legislation remains unknown. However, policymakers in the arts should be aware of the possible implications and should be planning right now to meet the potential contingencies.

Recent litigation has stressed the rights of mentally disabled persons to receive treatment appropriate to their needs. Many courts, under the rubric of "right to treatment," have mandated the provision of a wide variety of services within institutions to maximize the growth and potential of the residents. These recent reforms provide an excellent opportunity for inclusion of broad-based art and cultural orientation programs within the scope of mandated developmental services.

Education

Public Law 94-142, the *Education for All Handicapped Children Act of 1975,* can also provide an impetus for the expansion of art education. Although the arts are not specifically mentioned in the legislation, both the House and Senate committee reports accompanying the act conclude that the arts are an important part of the educational process for the handicapped child. House Report 94-332 includes the following language:

> The use of the arts as viable teaching tool for the handicapped has long been recognized. The arts have been used to reach children who have otherwise been unteachable. The cultural development of our society is reflected in art galleries and museums and the handicapped must not be excluded from exposure to this important aspect of our society.

The Senate Report 94-168 contains the following comments:

> Handicapped individuals have a normal probability of being creative and talented . . . The committee envisions that programs under this bill could well include an arts component . . . Such a program could cover both appreciation of the arts by handicapped youngsters, and the utilization of the arts as a teaching tool *per se.*

Developmentally Disabled

P.L. 94-103, the *Developmentally Disabled Assistance and Bill of Rights Act,* grants the authority to provide money ". . . to assist in the elimination of social, attitudinal, and environmental barriers confronted by persons with developmental disabilities." Although arts activities are not specified, grant monies could be used to develop programs for developmentally disabled persons in arts therapy, arts education, and creative arts. Innovative projects in the arts could aid in the elimination of those barriers noted in this legislation.

CONCLUSION

The importance of arts education, arts therapy and the arts as a profession for handicapped persons should be emphasized. Barriers of all types which preclude the participation of disabled persons from appreciation of and participation in cultural activities must be eliminated. Most decision-makers, however, are still unaware of the significance of the arts and consider them a low priority. Nonetheless, the arts are gradually becoming a more important life activity of handicapped individuals.

BIBLIOGRAPHY

Bragg, B.H., "The Mentally Retarded Deaf Child: Report of a Special Study Institute," Portland, Oregon: Lewis and Clark College, 1969.

Gallagher, Patricia A., "Procedures for Developing Creativity in Emotionally Disturbed Children," *Focus on Exceptional Children,* 4:6: 1-9, November, 1972.

Gilliland, Esther Q., "Functional Music for the Exceptional Child in the Special Schools of Chicago," *School Music Handbook,* Boston: C.C. Brichard, 1955, pp 585-591.

Irwin, Eleanor C. and McWilliams, Betty Jane, "Play Therapy for Children with Cleft Palates," *Children Today,* 3:3:18-22; May-June, 1974.

Malloy, Larry, *Arts and the Handicapped: An Issue of Access*, New York, New York: Educational Facilities Laboratories and the National Endowment for the Arts.

Neale, Marie D. "The Effect of a Broad Art and Movement Program Upon a Group of Trainable Retarded Children," Copenhagen Congress on the Scientific Study of Mental Retardation, August 1964.

Nesbitt, Neal, and Hillman, "Recreation for Exceptional Children and Youth," Denver, Colorado: Love Publishing Co., 1974.

Nuske, Karen, *Title I Report,* State Education Agency, Washington State, Unpublished material, 1975.

Pitman, Derek J. "The Musical Ability of Blind Children," *Research Bulletin, No. 11.* American Foundation for the Blind, October, 1965, pp. 63-80.

Smith, Jean Kennedy, Acceptance Speech, New York Humanities Conference, 1974.

Trotter, Virginia Y., "The Quest for Quality in Life," (Conference Evaluation Summary, State of Washington, 1975).

Tyszkiewiez, Magdalena, "Unintended Artistic Elements in the Drawings and Paintings of Mentally Retarded Children." *Psychiatria Polska* (Warszawa) 6:3:267-275, 1972.

(Other materials made available by the National Endowment for the Arts.)

ARCHITECTURAL ACCESSIBILITY

Awareness Paper Prepared By

Ronald L. Mace, AIA
Barrier Free Environments, Inc.
Fayetteville, North Carolina

TABLE OF CONTENTS

	Page
The Problem	151
Who is handicapped?	151
Numbers of disabled people	152
How barriers affect people	152
Why do barriers exist?	152
Professional awareness	152
The small numbers argument	152
Cost concerns	152
Achieving Accessibility	152
Construction regulation	153
Design standards	153
Use of standards in codes and laws	153
Standards for accessibility	154
Adopting ANSI	154
Performance vs. prescriptive standards	155
ANSI revision	155
Federal Efforts	155
Public laws	155
National Commission on Architectural Barriers	155
Architectural Barriers Act of 1968	156
Architectural and Transportation Barriers Compliance Board	156
Urban Mass Transportation Act 1964	156
General Accounting Office Investigation and Report	156
Tax incentives	157
Research	157
State Efforts	158
North Carolina	158
Handicapped code	158
Legislation	158
Special Office	159
Modifications	159
Public awareness	159
Massachusetts	159
Other States	159
Local Efforts	159
City codes	159
Mayor's Committees and Offices	160
Funding Sources	160
Other Efforts	160
Studies, conferences, workshops	160
First National Institute on Architectural Barriers	160
AIA Barrier Free Architecture Workshops	160
National Citizens' Conference	160
National League of Cities Study	161
International Symbol	161
National Center for a Barrier Free Environment	161

Cost-benefit Studies 161
Education of Professionals and Decision Makers 162
Public Awareness 162

Housing 163
Need 163
Standards 163
HUD housing programs 163
Veterans Administration 164
A&TBCB Housing Hearing 164
NAHRO Guide 164

Conclusion 164

THE PROBLEM

People are handicapped by a poorly designed environment that fails to meet their widely varying needs.

Who is Handicapped?

At some stage in life, every person may experience a condition under which he could be classified as handicapped. During the natural process of aging, from infancy to death, people pass through periods of varying ability and disability. We may define a handicapped person as someone who is prevented from using or doing a particular thing because of the design of a facility or the design of a piece of equipment.

The child or small person who needs to use a coin telephone and cannot reach the high coin slot is handicapped. The elderly person whose impaired vision makes it impossible to read scarcely legible signs and markings, the student whose study space is poorly lighted, the pregnant woman who must climb long flights of stairs, the mover who must carry a piano through a narrow door, as well as a person who uses a walker or wheelchair and cannot climb stairs or enter a toilet stall—all are handicapped by facilities. An environment that has been designed for a mythical average or "normal" person who is of average size and who possesses full and complete use of all physical, mental, and emotional faculties will not meet the needs of most people. Must it be necessary for one to be at the peak of human physical development to be able to enter our buildings and enjoy the many varied experiences our society has to offer?

Because of incomplete development, aging, accident, heredity, or disease, many people may not have complete use of all their senses or all parts of their bodies. The dysfunctions or disabilities resulting from these causes have been identified by Dr. Edward Steinfeld at Syracuse University as follows:

1. Difficulty interpreting information
2. Impairment of sight
3. Impairment of hearing
4. Loss of agility, reaction time
5. Prevalence of fainting, dizziness, poor balance
6. Incoordination
7. Limitation of stamina
8. Difficulty moving head
9. Difficulty lifting and reaching
10. Difficulty handing and fingering
11. Inability to use arms, shoulders
12. Difficulty bending, sitting, turning, etc.
13. Difficulty using legs and feet
14. Inability to use legs and feet
15. Hypesthesia (sensory loss)
16. Dimensional extremes

People suffering any one or a combination of these dysfunctions are disabled to varying degrees. The variations and possible combinations of these dysfunctions are almost limitless.

Numbers of Disabled People

While it may be possible to determine the approximate number of people who are aged or have a particular disease or injury type, it is impossible to determine which disabilities have resulted from these causes. Adding to the difficulty of determining how many disabled people there are is the fact that some disabilities are temporary as with broken bones or pregnancy; others are progressive, and others are permanent and constant. It is obvious that the number of disabled people is large; with improved rehabilitation methods and increased medical care, fewer people will die and the number of disabled people will increase.

Greater numbers of disabled people can be expected to lead active lives, hold jobs, and otherwise participate in society, if the design of buildings and adjacent space, as well as the selection of hardware and equipment, do not present obstacles for them. Great expense and effort in rehabilitation is thwarted by features such as curbs, stairs, difficult signs, steep slopes, slippery surfaces, extreme glare, ambiguous spaces, and long distances. These and other obstacles may be integral features of our buildings, outdoor spaces, hardware, equipment, and manufactured products. Although commonly called architectural barriers, they might more appropriately be called accessibility or environmental barriers in that they are present virtually everywhere.

How Barriers Affect People

If for some reason a person is limited in ability to move about freely, be it due to lack of transportation or a disability, it may:

- decrease opportunities for interaction with others and cause isolation, loneliness and social deprivation;

- reduce access to needed services and jeopardize safety;
- produce frustration, humiliation, and poor self-image;
- limit opportunities for employment;
- prohibit independent living.

Why Do Barriers Exist?

As man-made products, barriers are design elements planned and constructed by those designers, architects, engineers, and public and administrative officials who shape our world. Barriers are created inadvertently by designers who know little or nothing of the widely varying abilities of their "clients".

Professional Awareness

Architects must know about the size and performance level of the people for whom they design. Schools of design have in the past taught students to consider and design for the almost non-existent "average" person. Most designers, unless they happen to have had personal experience with disability, are totally unaware of the functional requirements of people with disabilities.

Most people, including designers, are unaware of the potential of people with disabilities to live active independent lives. Many designers, even after being informed of design requirements for the disabled, believe they need only consider disabilities when designing medical facilities, doctors' offices, and similar places which they presume are the only places disabled people go. Those designers perpetuate the concept of special facilities for disabled people and assume, for example, that office buildings need not be barrier free because disabled people do not hold jobs, or that grocery stores should not be thoughtfully designed because disabled people do not do their own shopping.

The Small Numbers Argument

Environmental barriers have kept disabled people from becoming independent and have restricted their mobility to the home or places of care such as nursing homes or institutions. Designers simply have not seen large numbers of disabled people holding jobs or moving about and therefore have difficulty believing that sufficient numbers of people exist to warrant their consideration in design. (This is a classic case of the chicken or the egg—which comes first, accessibility or visibility?) Some people who are aware of both how to design for all people and of the potential of disabled people still may not be fully aware of the great numbers of people affected or may not imagine that an able-bodied person may at any moment become disabled.

Cost Concerns

Design for accessibility often raises serious concern within the design and construction industry about extreme and unnecessary extra expense. Usually this concern is based upon misconceptions of what is required or upon an inefficient method or approach to solving the problems. Where accessible facilities have been constructed, it has been proven that overall there is very little, if any, increase in cost. In some cases there can be a savings if appropriate consideration is given early in the design of a facility. Two examples illustrate this:

1. Comment: Wider doors cost more.

Explanation: Yes, but a door which is six inches wider requires six inches less wall area, and walls cost more than doors thereby off-setting the cost of the wider door.

2. Comment: Accessible entrances will require expensive ramps.

Explanation: Yes, but only if floor levels are above ground level will ramps be necessary. If considered in early planning stages, the floor level can be placed close to ground level and accessibility can be provided with simple, inexpensive, ground level walks, thus eliminating the need for either ramps or stairs and effecting a considerable cost reduction.

Many designers may complete a design before considering people with disabilities. Such an afterthought or add-on approach may result in cost increases for ramps and other features which might have been eliminated by careful, early planning.

ACHIEVING ACCESSIBILITY

Construction Regulation

Design and construction are regulated in this country to protect the health, safety, and welfare of the public. Contractors, many designers, and all architects and engineers must be licensed to practice their professions. Licensing of these

individuals is done in each state and requires a combination of education and experience along with the successful completion of a series of examinations.

Building construction methods and design practices are regulated by building codes and design standards adopted by federal and state governmental agencies. The construction industry is required either by law or as a stipulation for funding to see that buildings and other facilities comply with these general requirements. Architects and other designers are required to include these legislative requirements in their planning. Building codes specify how, and with what kinds of materials, buildings may be constructed to protect the public from harm.

Design Standards

Standards are guidelines or recommendations for design which are intended to promote understanding within an industry and standardize design practices. Standards may be developed on the design of virtually anything and they are usually established by voluntary groups for the purpose of recommending standard practices and procedures for accomplishing a specific task or goal. Groups such as the American National Standard Institute (ANSI), National Fire Protection Association (NFPA), National Sanitation Foundation (NSF), and various manufacturing associations bring together professional people and experts to write standards in their area of concern. It is important to remember that standards are only voluntary or recommended practices and procedures and do not have enforcement or legislative authority until they are adopted by a body or agency which has such authority.

Use of Standards in Codes and Laws

Building codes are legislative construction requirements which have authority of law. Model building codes are established by associations of building officials as recommendations to the states in their regions. These also are recommendations until they are adopted by legislative acts. There are four national model codes in the United States: Building Officials and Code Administrators (BOCA), Uniform Building Code (UBC), International Congress of Building Officials (ICBO), and Southern Standard Building Code (SSBC). Organizations may adopt national standards as part of their recommended codes or may establish their own requirements.

States and/or cities and counties may establish building codes by adopting one of the model codes, or by adopting national standards directly, or by developing their own state, county or city requirements. Not all states have state-wide building codes. Some have voluntary state codes in which the localities do not have to comply unless they elect to adopt the state's code. Construction funding sources such as federal agencies or private foundations may develop standards of their own or adopt national standards as a part of their construction regulations or stipulations for funding.

Each time a standard is adopted by a code or regulatory agency and each time a code is adopted by a state or municipality it may be modified to meet local needs, pressures or opinions. Thus, standards may not remain intact through these possible transformations.

Both agency regulations and state codes may have sanctions for failure to comply. Agencies may enforce their regulations by withholding funds or approvals. States or municipalities enforce codes with legal authority specified by their state legislatures.

Standards for Accessibility

Standards are an effective way of bringing about unanimity of thought and coordination of purpose because standards affect government, industry, labor, and consumer interests. The President's Committee on Employment of the Handicapped (PCEH) and The National Society for Crippled Children and Adults (NSCCA, the Easter Seal Society) conceived the idea of an accessibility standard for disabled people to help increase professional and public understanding and response to the problems of people with disabilities. In 1959, individuals who were interested in the accessibility problems of the disabled were invited to meet with the PCEH, NSCCA, and the American Standards Association (ASA). The result of that meeting was the beginning of an ASA project to develop a national accessibility standard. The project was sponsored by PCEH and NSCCA. With financial support from NSCCA a grant was awarded to the University of Illinois to conduct the necessary research and develop the project.

A steering committee with representatives from ASA, the sponsoring organizations, and govern-

ment agencies, and experienced individuals was appointed. A standards committee, composed of 35 representatives of all relevant professions, trades, societies, associations, governmental agencies, and organizations for the disabled, was selected to assist with and approve the standard. Dr. Timothy Nugent of the Rehabilitation Center, University of Illinois, served as the secretariat to develop and test the proposed standards.

The standard became known as ASA project A117.1 and was entitled "Making Buildings Accessible to and Usable by the Physically Handicapped". In October 1961, it was officially approved by the committee and adopted by the American Standards Association. ASA was later changed to American National Standards Institute (ANSI) and the standard became known as ANSI A117.1 or "ANSI" Standard. The ANSI Standard set forth minimum design requirements for 16 different aspects of a building (such as grading, parking lots, walks, entrances, doors and toilet rooms) to make it accessible to and usable by the physically handicapped.

Some problem areas identified in the research phase of the development of the ANSI standard did not find their way through the committee consensus process and were not included due to cost and other concerns of committee members. It must be remembered that this first ANSI committee was working in an area totally unfamiliar to the design and construction industry. This first generation standard clearly would need updating after a trial in the field and as awareness and understanding of methods of meeting the requirements eliminated the apprehension.

Adopting ANSI

In the years following its completion the pioneering ANSI Standard became the basis for most state and federal legislation, regulations, and building codes. Seminars and workshops were conducted across the country and educational and promotional materials were developed to assist in implementation of the standard. Progress was made but much of the early legislation simply referenced the Standard and often failed to include provisions for enforcement. The Standard was on the books, but was not universally implemented. In fact, a survey in 1968 indicated that most professional people were still completely unaware of the Standard's existence.

As awareness increased and pressure was brought to bear, states and agencies adopted the standard and frequently modified or added to its requirements in attempts both to include areas omitted in the 1961 ANSI Standard and to meet local agency pressures and needs. The result has been another problem for implementation—proliferation of state and national standards, codes or requirements which conflict. Today there are nearly 75 differing standards and codes for accessibility. Architects and designers may find themselves in a quandry as to which one takes precedence. The 1961 ANSI Standard is still the fundamental standard used in most federal agencies and referenced in most state legislation. A General Accounting Office study report in 1975 states:

> Even though the ANSI (1961) Standard was prescribed by each Federal Agency and represents an important step toward promoting accessibility in public buildings, it is generally considered an incomplete minimum standard.

The report further lists some of the deficiencies of the Standard:

1. It is not specific in certain technical requirements which results in varying interpretations,
2. It does not include housing and
3. ANSI, like other standards, does not specify what facilities are to be covered.

Performance vs. Prescriptive Standards

Another problem with accessibility standards and codes has been the exclusive use of either prescriptive standards which state absolute dimensions, or performance statements which describe the task to be accomplished in human functional terms and leaves the choice of an exact design solution to the designer. The following example illustrates the difference: A prescriptive standard might say, "Switches and controls must be no higher than 40" above the floor." A performance standard would say, "Switches and controls must be within reach of and operable by people in wheelchairs and small people."

On one hand, the performance standard requires the designer to know the reach range of both people in wheelchairs and small people, but allows a variety of solutions which might make the requirement more widely applicable. To do this, the performance standard must either provide the *criteria* upon which the designer can base his decision, or assume that the information is available to him. In this case the *criteria* would be

information on the reach and operating abilities of disabled people. If this information is not readily available, it may be necessary for a designer to spend unreasonable amounts of time in researching each requirement. On the other hand, prescriptive standards which offer exact solutions are often too absolute and, in instances where their requirements cannot be met, they offer no alternative or explanation of purpose and often are simply not complied with.

The most practical standard in terms of implementation is one which gives prescriptive data where it must be absolute and also provides performance descriptions with appropriate criteria where necessary. Such a combined prescriptive/performance standard would give the designer an immediate decision and then, if that requirement could not be met, the standard would provide the performance statement of task and criteria so that the designer could devise an acceptable solution. No such combination standard for accessibility exists today.

ANSI Revision

In June of 1974, the Department of Housing and Urban Development joined the President's Committee on Employment of the Handicapped and the National Society for Crippled Children and Adults to begin a project to revise the ANSI Standard and expand it to include housing and other concerns. A two-year research contract was awarded to Syracuse University to develop the new standard and carry it through the American National Standards Institute Standards Committee process for consensus and adoption as the new ANSI Standard for accessibility.

A thorough review of all related activities has been completed and an exhaustive State of the Art Report has been prepared. This Report is available from the Syracuse University, School of Architecture Research Office.

The research team directed by Dr. Edward Steinfeld has tested disabled people in the performance of all types of tasks to empirically determine accurate criteria for design. The two years of testing and test results have been monitored by panels of individuals representing industry, professions and consumer groups. The results of the testing and panel reviews have been incorporated into the final draft of the proposed standard. After final rewriting and editing, in late winter or early spring of 1977, the proposed new standard, incorporating both performance and prescriptive data, will be reviewed by the 66 organizations which make up the American National Standards Institute Committee for the accessibility standard. Dr. Timothy Nugent is chairman of the ANSI reviewing committee. Each member organization will vote on the adoption of the draft some time in the spring or summer and if consensus is reached it will officially become the new ANSI Standard.

Once in effect, it will automatically be incorporated into those laws which specify compliance with the latest edition of ANSI A117.1, or it can simply be added to existing legislation. It is hoped that the new ANSI will replace many of the state and local codes and standards so that it can be uniformly implemented in all states.

FEDERAL EFFORTS

Significant progress has been made in the past 10 years on the federal, state, and local level in promoting architectural accessibility, Federal efforts have included passage of the following public laws and other activities:

Public Laws

National Commission on Architectural Barriers to the Rehabilitation of the Handicapped. Public Law 89–333, the Vocational Rehabilitation Amendment of 1965, established a National Commission on Architectural Barriers to the Rehabilitation of the Handicapped in the Department of Health, Education and Welfare (HEW). Under this law, the Commission was charged with the task of studying the problems of making all facilities and buildings accessible to disabled people. The Commission studied both public and private activities in barrier removal to determine the extent of the problem and recommend in its final report (see *Design for all Americans*) that laws be enacted to require that all buildings owned or leased by the Federal Government be constructed without barriers. They further recommended that barriers in existing federal buildings be removed and that HEW work with other agencies to develop standards for barrier free design.

Architectural Barriers Act of 1968. Public Law 90–480 was passed by Congress following up on the recommendation of the National Commission on Architectural Barriers to the Rehabilitation of the Handicapped. This law requies that any

facility built with or receiving federal funds must be free of barriers. It requires the secretaries of the General Services Administration (GSA), Department of Housing and Urban Development (HUD), the Department of Defense (DOD), and the Department of Health, Education and Welfare (DHEW) to issue standards for federal buildings. These agencies were also directed to undertake surveys, investigations, or other actions to assure compliance.

The standard issued was ANSI A117.1; little was done to assure compliance so the effectiveness of the law was minimal. Recently HEW, GSA, VA, DOD, and other agencies have independently developed their own guidelines for accessibility, adding to or modifying the original ANSI Standard. The result has been the proliferation of federal standards which frequently do not agree and have made universal application impossible.

The Architectural and Transportation Barriers Compliance Board. Public Law 93–112, The Rehabilitation Act of 1973, section 502, established the Architectural and Transportation Barriers Compliance Board (A&TBCB). The primary purpose of the Board is to enforce compliance with public law 90–480 and thus ANSI A117.1 in all federally funded construction. Congress intended the Board to take an aggressive role in carrying out its compliance function. This is indicated by the enactment of Public Law 93–516, the Rehabilitation Act Amendments of 1974, which provided that a compliance order of the A&TBCB could include the withholding or suspension of federal funds for a non-complying building.

The A&TBCB's other functions include investigating problems of disabled people and recommending solutions both in housing and transportation, seeking alternative solutions to these problems, increasing public awareness and providing information.

Ironically, the very makeup of the Board (the members are the heads of the other agencies, Department of Health, Education and Welfare, Department of Transportation, Department of Housing and Urban Development, Department of Labor, Department of the Interior, Department of Defense, General Services Administration, United States Postal Service, Veterans Administration) has limited the effectiveness of the Board's compliance/enforcement efforts because each of the member agencies has construction activities and may be subject to compliance action which they can veto as members of the A&TBCB. There is already evidence that the member agencies will not allow the Board to fulfill its compliance role or even offer technical assistance with implementation of the standards.

People having evidence or complaints about federally funded facilities not in compliance with Public Law 90–480 requiring accessibility should write to the A&TBCB so that appropriate corrective action can begin.

Urban Mass Transportation Act of 1964 Section 16(a). This act restates the rights of disabled people to utilize transit facilities and states that special efforts shall be made in planning and design of all facilities to assure their accessibility.

General Accounting Office Investigation and Report. At the request of members of Congress, the General Accounting Office initiated an investigation of the federal departments' and agencies' activities to comply with the Architectural Barriers Act of 1968 and issued a report to Congress in 1975 on the effectiveness of the law. GAO's conclusion was that "lackluster compliance with the Architectural Barriers Act has had only minor effect on making public buildings barrier free". The report also cites agency inaction and confusion, deficiencies in the standards and deficiencies in the language of the act itself as the reasons.

Highlights of GAO's recommendations to Congress include:

1. Clarify and mandate the intent of the act.
2. Require the named agencies to establish a continuing system of surveys and investigations to insure compliance with prescribed standards.
3. Give the Architectural and Transportation Barriers Compliance Board authority to coordinate development of standards by each agency charged with construction responsibility to eliminate barriers in federally financed buildings.
4. Require agencies to clarify and improve the standards and to establish appropriate controls, surveys and investigations to insure that buildings are designed barrier free.
5. Expand the act to cover government *leased* facilities.

Tax Incentives

Included in the Tax Reform Act of 1976 is a section establishing a federal tax incentive for eliminating barriers. Patterned after a bill established in North Carolina, the Tax Reform Act of 1976 contains a special clause granting tax relief

to businessmen who remove barriers to the handicapped.

Generally, costs incurred to improve property used in a trade or business must be capitalized and may be depreciated over the useful life of the property.

Section 2122 of the Act provides an elective current deduction for the removal of architectural and transportation barriers to the handicapped and elderly (age 65 and over) in any facility or public transportation vehicle owned or leased for use in a trade or business. The Act defines handicapped individuals to include the deaf and blind. The barrier removal must meet government standards. The maximum deduction is $25,000 per taxpayer for any taxable year. The deduction is effective for taxable years beginning after December 31, 1976, and ending before January 1, 1980.

Research

One of the difficulties in the barriers movement has been the inadequate information about people with disabilities. Information on the abilities, functioning, needs, and dimensions of disabled people has not been available. Most agencies directly involved with construction have one or more research contracts in progress to determine some of this much needed data for their future efforts at barriers prevention and removal.

HUD, for example, in addition to the proposed ANSI revision, has a number of research projects in progress developing information on various aspects of housing for people with disabilities. The VA, the HEW Office of Developmental Disabilities, GSA, A&TBCB and others have major contracts to collect better or new information upon which future decisions can be made.

Some of the recent government research includes:

1. Provisions for Elderly and Handicapped Persons
   - Department: Department of Transportation's Federal Highway Administration
   - Purpose: Guidelines for design of streets and highways
   - Contractor: Georgia Institute of Technology, College of Architecture
2. Mobile Homes for Handicapped People
   - Department: Department of Housing and Urban Development (HUD)
   - Purpose: Development of safe and accessible mobile homes as alternative housing for the handicapped
   - Contractor: Saint Andrews Presbyterian College, Laurinburg, N.C.
3. Accessible Environments for the Disabled
   - Department: HEW Office of Developmental Disabilities
   - Purpose: Development of strategies for orienting the building community to be responsive to the needs of the disabled
   - Contractor: Building Research Advisory Board, National Academy of Science
4. Building Criteria for the Disabled
   - Department: Architectural and Transportation Barriers Compliance Board
   - Purpose: Developing design criteria for use in evaluating design standards
   - Contractor: Building Research Advisory Board, National Academy of Science
5. Barrier Free Villages in New Communities
   - Department: HUD
   - Purpose: Demonstrate the feasibility and process of designing a totally barrier free environment for new communities
   - Contractor: Peoples Housing, Topanga, California
6. Barrier Free Site Design
   - Department: HUD
   - Purpose: Guidelines for accessible site development
   - Contractor: American Society of Landscape Architects Foundation
7. Housing Research
   - Department: HUD
   - Purpose: Evaluate the hypothesis that a percentage of all multi-family housing should be accessible to the handicapped
   - Contractor: Battelle Laboratories, Columbus, Ohio

A more complete list of current research on the disabled should soon be available as a result of a study of such projects being conducted for A&TBCB.

STATE EFFORTS

All 50 states have legislation of some type dealing with the barriers problem. Some have enacted only token legislation with no effective implementation or enforcement. Others have a series of far-reaching and effective laws and have developed technical assistance programs, economic support, and enforcement systems. Several states have overcome administrative and attitudinal problems and have established agencies or

offices specifically to oversee their barrier free legislation.

The states where progress in successful barrier prevention and removal programs has been most significant have used a combination of the following essential activities:

1. strong anti-discrimination legislation and building code requirements;
2. technical assistance and training for designers and building inspectors who must comply with or enforce the requirements;
3. public and professional awareness programs;
4. enforcement procedures with power to deny construction or occupancy permits, withhold funding, impose fines or imprisonment; and
5. financial incentives such as tax credits.

North Carolina and Massachusetts are two states which have different, but effective programs. They are outlined here as examples.

North Carolina

North Carolina has a uniform building code which is applicable state-wide. The code is administered by the Department of Insurance, Engineering Division. Department staff and locally appointed city or county building inspectors review plans and inspect buildings before, during, and after construction for compliance with the code. The code is developed by a building code council, and has penalties imposed by law for non-compliance.

In 1968, the North Carolina Building Code Council adopted the ANSI A117.1 Standard for accessibility and included it as a recommendation. The language used the term "should" instead of "shall" for every requirement in the Standard. Hence, the 1968 Standard was not taken seriously by the construction industry and was totally ineffective and unenforceable. It also followed the basic ANSI format, was vague, and narrow in scope, and nothing was done to promote or enforce its requirements.

Handicapped code. In 1971, a Governor's Study Committee on Architectural Barriers was appointed to study the problems of disabled people in North Carolina and to make recommendations to the State. The Committee's recommendations, published as a *Final Report* in 1972, resulted in the following:

- In 1973–74 the handicapped section of the building code was revised and expanded in scope to include *all* new and remodeled buildings in the state both publicly and privately owned with the exceptions of single- and two-family residences and portions of heavy industrial facilities such as refineries. After lengthy negotiations with industry representatives the revised code section with "shall" language was adopted by the Council in 1973.
- In 1974 the handicapped section of the building code was completely illustrated, paraphrased in simple language, and augmented with preferred solutions. The latter were illustrated with explanations for the requirements given in performance-type language. It was felt that simplified language and illustrations would make the requirements more easily understood by more people.

Legislation. Following the publication of the *Final Report* the following significant legislation was enacted:

- Statute 168–1 through 168–8, "Bill of Rights for the Handicapped," establishes the rights of disabled people to full and free use of all facilities and accommodations afforded to other people, including streets, transportation, employment, rehabilitation, housing and special provisions for the blind. This legislation goes far beyond the building code in requiring use and access to all facilities, new or old.
- Statute 136–44.14 requires installation of curb cuts or ramps at all new or remodeled intersections in the state.
- Statute 105–130.5(a) 8.b (10) (c) (24) provides tax credits for removal of barriers to the handicapped.
- Statute 105–130.22 provides credits against income tax for the construction of dwelling units to meet North Carolina building code standards for the handicapped.

Special Office. In 1974 a Special Office for the Handicapped was established within the Department of Insurance specifically to administer the handicapped code requirements. Effective implementation of code requirements necessitates interpretation and technical assistance; so the Special Office was established and staffed with an architect to provide such assistance.

The functions of the office are: (1) to provide technical assistance to industry and individuals on compliance; (2) review requests for waivers or amendments to accessibility requirements; (3) develop awareness and training materials on design for and abilities of disabled people; and (4)

assist with further amendments to the handicapped code requirements.

To date, the Special Office has developed a series of public and professional awareness materials including publications, brochures, a technical slide show on design requirements, an awareness slide show for public information, and TV spots. The Office regularly conducts seminars and workshops with building inspectors, architects, and builders on code requirements and design solutions to both educate and receive comments from the field on problems of compliance.

Modifications. In view of recent anti-discrimination legislation, North Carolina has begun modifications to existing state facilities to make them accessible. The General Assembly has appropriated several million dollars to begin the modifications. Further, a new publication of fully illustrated guidelines for modifications to existing buildings has been produced by the Special Office to assist agencies and individuals with modifications for accessibility.

Public awareness. The State Personnel Office and the Special Office for the Handicapped have both initiated public awareness programs on the abilities and experiences of disabled people, code requirements, affirmative action, hiring policies, rights, and services.

Massachusetts

In 1974, an Architectural Barriers Board was established within the Massachusetts Department of Public Safety. The Board membership includes both disabled and able-bodied professional people who are charged with the responsibility for developing and enforcing standards for barrier free design in Massachusetts.

The Board has the authority to direct State building inspectors in their enforcement of the regulations and to bring court action in cases of non-compliance. It meets regularly to review cases and hear requests for waiver from the requirements.

The state has also established a training course for building inspectors to prepare them for their enforcement role in the compliance of barrier free standards.

The Massachusetts system is noteworthy and represents, with its Board, another effective way to remove and prevent barriers. The Board's standard is a very comprehensive one. It must be noted, however, that the scope of its coverage only includes all publicly *funded* buildings, but excludes many privately owned but publicly *used* facilities. Privately owned commercial buildings, for example, must exceed two stories in height and employ more than forty people before they must comply. Theaters and other places of assembly must seat more than 150 people before they are required to comply.

Other States

There is much to be learned from the experiences of each state. When reviewing a state's activities as a possible model it is important to look at the content of the technical standard, the scope of its application (i.e. which buildings does it apply to and which are exempted), and its enforcement procedures. In addition, one should look for special legislation on rights or accessibility.

Administrative procedures are different in each state. In one state it may be a special construction agency which has control of building regulations. In other states the fire marshall, insurance department, public safety department, development board or budget department may have such authority and can impose or enforce barrier free provisions.

Citizens' groups and associations have often found support from state rehabilitation agencies in locating the proper state agency or legislator to see in initiating barriers legislation. It usually takes a concerted effort by informed disabled people, rehabilitation specialists, private associations, state agencies and concerned legislators to change state law and procedures. But it can be done.

The most recent survey of state codes for barrier free design was done in 1975 as part of the HUD/ANSI Standard Project at Syracuse University.

Other states where enforcement procedures and information systems are being developed include New York, Illinois, Michigan, Iowa, California, and New Mexico. Additional information may be available from their rehabilitation or construction regulatory agencies.

LOCAL EFFORTS

City Codes

Cities often have their own building codes. This is especially true in states where the state building

code is voluntary. In such states the cities and towns may elect to adopt the state code or may develop their own. Many larger cities have independent codes and some have included provisions for making community facilities barrier free.

Mayor's Committees and Offices

Local Mayor's Committees for Employment of the Handicapped often have architectural barriers sub-committees. These volunteer groups of interested individuals can be instrumental in changing local codes and ordinances. New York City and Philadelphia also have Mayor's Offices for the Handicapped. These offices are staffed by full time professional people who act as liaison between the city administration and disabled people. The activities of the mayor's offices include a variety of service and support programs and they have promoted many barriers removal projects.

FUNDING SOURCES

In addition to the tax incentive for barriers removal mentioned previously, there are numerous government agencies and private funding programs which may be applicable to barriers removal projects. One source is the Federal Community Development Funds which are being returned to local communities. These monies may be used for barriers removal projects and many communities have begun modifying buildings for accessibility and ramping curbs as part of their community development projects.

The Architectural and Transportation Barriers Compliance Board published in May 1976 a *Funding Guide for the Removal of Environmental Barriers.* This document describes government agency and department programs which have funds applicable to barriers removal projects. It also gives eligibility and contact information.

Educational Facilities Laboratory and the National Endowment for the Arts have published a *Funding Sources Guide* for programs and facilities to make the arts accessible to the disabled.

Both of these recent publications are available and contain the best available information on possible financial support for barriers removal projects.

OTHER EFFORTS

Studies, Conferences, and Workshops

Numerous studies, conferences and workshops in recent years have substantiated the continuing problem of accessibility to the disabled. Even conferences convened for other issues have had to recognize how environmental barriers prevent the accomplishment of their goals.

Policy statements and reports from those conferences have called for increased efforts by federal and state governments, provided new information on costs, increased awareness, and generally focused attention on the problems and possible solutions. These significant events have helped bring about activities which are continuing today.

The First National Institute on Architectural Barriers in 1966. This Institute, sponsored by the President's Committee on Employment of the Handicapped and the National Society for Crippled Children and Adults, resulted in barriers removal workshops as part of state and regional organization meetings.

American Institute of Architects: Barrier Free Architecture Workshops. These two-day workshops for architects were funded by the Rehabilitation Services Administration and conducted by AIA in ten cities in 1969. The workshops were intended to develop professional awareness and to determine how similar activities could be sustained. The workshops were a good beginning toward professional education in barrier free design but they reached relatively few people and have not been sustained.

The AIA, however, formed a professional task force on barrier free design within the Institute which has been active for several years. Unfortunately, AIA decided to abolish its task force this year (1976) for unspecified reasons.

National Citizens' Conference on the Rehabilitation of the Disabled and Disadvantaged. This citizens' conference was convened in 1969 by the Secretary of Health, Education, and Welfare. It was concerned with all aspects of rehabilitation, and barriers removal was a necessary component. A report entitled "People Power" and a brochure on barriers elimination were published.

National League of Cities Study to Eliminate Architectural Barriers. This study was sponsored by the Rehabilitation Services Administration in 1966 to examine state and local legislation and practices of architects and trade associations on

barriers removal issues. The League, as a part of its study, did the first comparative cost analysis of barriers removal in new and existing facilities (see cost-benefit studies below). The final report entitled *State and Local Efforts to Eliminate Architectural Barriers to the Handicapped* was published in 1969.

International Symbol

In 1969, the 60 national member organizations of Rehabilitation International voted to adopt an international symbol for accessibility. Use of this symbol has been promoted through the various standards to identify buildings or portions of buildings which are accessible to individuals with disabilities. It has also been used to mark accessible routes of travel to facilities which are accessible.

This symbol has been useful and helpful where standards require minimum numbers of facilities to be accessible, such as one toilet room on a floor. If there are five toilet rooms on a floor and only one is accessible, signs identifying the room and directing people to it are essential. If all toilet rooms on every floor were equally accessible there would be no need for such a symbol or sign.

The International Symbol is not copyrighted and its use cannot be controlled since it is already widespread. The symbol was intended to be used only on facilities which are truly accessible and usable. Unfortunately, its use has been abused and its effectiveness weakened when people have displayed the symbol on buildings which are not usable by the disabled.

In some instances use of the symbol is stigmatizing and has negative results. Coin telephone installations are one example. Many standards have required that some coin telephones be installed with coin slots 48" above the floor so they can be reached by wheelchair users and small people. Often the standards have also required that these low phones be identified by the International Symbol. The able-bodied public, seeing those telephones identified as "for the handicapped" will not use them, either because they believe that they are not for general public use or because they do not want to be identified as handicapped. Phone companies remove coin telephones which do not make money. The lower revenue produced by the "special" telephones has led to the telephone companies' current proposal to raise the phones to the standard height which is out of reach of many disabled people.*

Use of the symbol in new facilities will continue to be necessary as long as the standards do not call for all facilities to be accessible to all people. It will also continue to be needed as portions of existing buildings are modified to accommodate people with disabilities. The symbol must be applied with reason and sparingly so as not to stigmatize the disabled and set them and facilities designed for their use apart as something different or special.

National Center for a Barrier Free Environment

The National Center for a Barrier Free Environment, incorporated in 1974, is a voluntary membership coalition of groups and individuals active in promoting barrier free design. A private non-profit corporation, it is open to all who are concerned with environmental barriers. Membership includes a subscription to *Report*, an excellent bi-monthly statement of nationwide information and activities, and other materials and services provided by the Center. Member organizations include the President's Committee on Employment of the Handicapped (PCEH), National Society for Crippled Children and Adults (NSCCA), Paralyzed Veterans of America (PVA), American Institute of Architects (AIA), Goodwill, and others.

The Center serves as a central clearing-house for information on efforts to prevent and remove environmental barriers. It also represents the first time that a coalition from the private sector has formed to promote barriers elimination.

Cost-Benefit Studies

The National League of Cities' study in 1966 was the first attempt to analyze costs for barrier

*American Telephone and Telegraph (AT&T) is proposing to install standard coin operated phones 54 inches above the floor. This is 6 inches higher than the 48" standard that had been accepted for the disabled. AT&T admits that their extensive research efforts to validate the 54" height has proven that phones at that height will exclude what they call an "insignificant" number of disabled people from using the phones. Some experts disagree with the 54" figure because phones placed at that height will be out of the reach of many disabled people. Those people in wheelchairs who can reach 54" must have large clear floor spaces in order to maneuver parallel and close to the phone. Such space is not available in phone booths. Therefore, phones at 54" installed in booths will not be usable by a larger percentage of disabled people than AT&T research indicate. The issue is not yet resolved.

free design. This study looked carefully at three typical public buildings and the costs of each feature. The study concluded that in the three building types studied—a civic center, a city hall, and a hotel—costs for omitting barriers in the design phase would not exceed one tenth of one percent of the cost of the building. Costs in other building types including both low and high rise, were determined to be less than one-half of one percent unless an elevator had to be installed, in which case the extra costs went to two and one-half percent over the estimated costs. Costs for removal of barriers after construction by addition of ramps, widening of doors, etc., were determined to be one percent of building costs.

Another cost analysis is being conducted by Syracuse University as part of the revision and expansion of the ANSI Standard for HUD. This study will identify comparative costs of individual features required for barrier free design.

Cost studies have also been conducted as part of various state efforts and have thus far confirmed that costs for barrier elimination are very low when considered in the initial design phase.

One executive in charge of facilities construction for a large corporation which voluntarily initiated a barrier free design program for its facilities across the country has said his company has been unable to identify *any* increase in costs for their accessible buildings.

Education of Professionals and Decision Makers

Some federal agencies and states have initiated programs of awareness and training on design for the disabled for their architects and engineers. Schools of architecture have been encouraged to begin incorporating design concerns for the disabled into their curricula. Thus far approximately six schools have some type of elective course or seminar available to students. Many more schools will need to follow their lead if this effort is to reach all designers. Also, design for the disabled must be included in the curricula of other disciplines such as engineering, interior design, product design, occupational and physical therapy, and counseling to reach all those whose decisions may affect a disabled person's ability to live independently.

The practicing engineer or architect whose educational experience does not include concerns for the disabled must also be made aware through continuing education programs, self-instruction manuals, or special workshops such as AIA's 1969 barrier free architecture workshops. These training courses must be made available continually for many years to come.

A recent change in the licensing examinations for architects is the inclusion of questions on barrier free design. This and other incentives will hopefully encourage the educational system to further efforts.

Training for designers in design for the disabled has only barely begun and a great deal more will be required before we can expect design professionals to understand the needs and abilities of disabled people, the simplicity with which they can be accommodated, and the small costs involved.

Public Awareness

Public awareness of the abilities of disabled people and the resulting acceptance is an essential ingredient in any barriers removal program. Once negative attitudes or misconceptions about disabled people have been dispelled by exposure to their aspirations and abilities, co-operation seems to begin. Demonstration projects have taken place in many states to publicize barriers. Films, videotapes and TV spots have been used by the President's Committee on Employment of the Handicapped and other agencies and organizations.

Progress has been most rapid in those states which have had effective awareness activities or lobbying efforts. Media representatives such as radio and television station executives, newspaper and magazine publishers, and editors and directors of advertising and public relations agencies are an asset to any campaign.

It is important to remember that barriers most often exist because people do not know what disabled people can do. The purpose of an awareness program is to inform.

These efforts have been effective but usually localized. There is a need for a concerted nationwide awareness program in addition to local programs. The Developmental Disabilities Office of the Department of Health, Education and Welfare has completed, through a research grant, a study of methods for implementing a nationwide public awareness program for developmental disabilities. The program is the same regardless of disability and the report for that project, *Recommendations and Guidelines for a National Public Awareness Effort for Developmen-*

tal Disabilities, outlines procedures which are universally applicable.

HOUSING

Need.

Disabled people who lack the financial resources to build or modify their own homes will find their housing choices to be severely limited or have no choice at all. One reason for this shortage of adequate housing is that standards and legislation for accessibility have not applied to housing. The competitive housing industry has not seen a potential market in housing designed for the disabled and has been reluctant to build accessible units. Fears and misconceptions about disabled people, especially the severely disabled and mentally handicapped, have caused other groups to oppose the construction of accessible homes. In addition, zoning laws often prohibit group homes. As a result many disabled people who might be able to live independently must remain in institutions or nursing homes or live dependent upon others.

As the disabled population has increased this housing problem has become increasingly acute. In some instances groups of disabled people have come together to build their own accessible group housing (apartments) to meet their commonneeds. Government agencies have supported such housing efforts with grants, loan guarantees, or housing assistance programs. However, there have not been enough of these sponsored housing projects to meet the need, and even if there were, such projects require that the disabled be satisfied to live together in segregated, specially built housing, something many disabled people are not willing to do. Still little or no choice may exist.

A National Conference on Housing and the Handicapped was held in Houston in 1974. This conference, sponsored by organizations for the disabled, federal agencies, consumer groups (disabled individuals) and rehabilitation organizations, identified many of the housing problems of disabled people, recommended solutions and located resources. One recurring theme of this conference was the need for a range of choices in housing so that disabled people could enjoy the same freedom of choice of location and housing type as other people.

Standards

The HUD/ANSI Standard revision has expanded its scope to include housing. The research team at Syracuse is developing housing standards which may be incorporated into the HUD Minimum Property Standards* and in regulations for their various other housing programs. The concepts of adapted and adaptable housing are being developed so that all housing can be either specially designed for disabled people or easily converted.

Standards for *adapted* housing will include all features necessary to accommodate a person with a disability. These might be applied where housing is being constructed specifically for disabled occupants. Standards for *adaptable* housing would include basic space and structural requirements to accommodate features for disabled people, but would not require installation of the specialized features. For example, walls might be reinforced so that grab bars can be easily added later. Such standards might be applied to all housing units constructed so that they could be easily converted to adapted units should a disabled person buy or rent. Specific features could then be custom tailored to the individual's needs, and the entire conversion would not require expensive major structural changes or additions. If these standards are included in HUD and other agency regulations for housing, disabled people may have a better chance of finding adequate housing in years to come.

HUD Housing programs

HUD has housing programs which provide monies to assist disabled people in various ways. Funds are available to communities for removal of architectural barriers and for remodeling of homes to make them accessible. HUD also insures costs for construction or rehabilitation of multi-family housing for individuals with disabilities. The HUD housing assistance payments program provides rent subsidies for low and middle-income handicapped people.

Eligibility for these various housing programs depends, in the case of assistance payments, on the extent of the individual's disability, and on

*HUD Minimum Property Standards for housing must be met for all Federal Housing Administration (FHA) loan guarantee projects.

type of sponsorship (non-profit, profit, corporate, public) for the housing.

HUD has so far assisted with development of these eight buildings designed for occupancy by disabled people: Vistula Manor, Toledo, Ohio; Pilgrim Tower, Los Angles, California; Center Park Apartments, Seattle, Washington; Walter B. Roberts Manor, Omaha, Nebraska; Highland Heights, Fall River, Massachusetts; New Horizons, Fargo, North Dakota: Independence Hall, Houston, Texas; and Creative Living, Columbus, Ohio. Information on these housing projects may be obtained from their directors or from HUD.

Veterans Administration.

The VA also is authorized to assist certain disabled veterans in acquiring suitable housing units, and can fund modifications to existing homes, additions, or purchase of new homes.

A&TBCB Housing Hearing.

In 1975 the A&TBCB held a national hearing on housing for the disabled. Testimony at the hearings from industry, disabled people, government, and others substantiated the problems of disabled people and of the housing industry in trying to provide housing for disabled people. *Freedom of Choice,* the Board's report to the President and Congress on housing needs of handicapped individuals, includes recommendations for actions to help resolve the problems.

NAHRO Guide.

The National Association of Housing and Redevelopment Officials in conjunction with the help of the International Center for Social Gerontology, is producing a guide for local housing entitled *Housing for the Handicapped and Disabled: A Guide for Local Action.* This guide is intended for use by individuals who are interested in providing housing for the disabled and find themselves thwarted because they are unfamiliar with the services needed, with government programs and "because they are almost totally unfamiliar with housing, housing finance, housing construction and rehabilitation, or even buying or renting a building and the complex technicalities that go with it." (*Housing for the Handicapped and Disabled*) This guide through the complexities of housing for the disabled should be available in 1977.

CONCLUSION

A sensitively designed environment provides opportunities for education, employment, housing, and recreation for all people. Years of experience have proven that accessibility is possible without sacrifice of function or major additional cost. Legislation has established the necessity for barrier free facilities. Research is adding new information on the abilities of disabled people. Technical design information is available, and new standards have been developed.

Better information will always be needed, and industry practices will continue to change as new technologies develop. Those closest to the problems know that accessibility can be achieved now and they know how to accomplish it.

The challenge now is to find effective strategies for changing practices within the design and construction industry. Training programs as an integral part of university curriculum, various incentives and awareness activities and increased exposure of active disabled people must be encouraged. The "specialness" of past design solutions must be de-emphasized and the universality of good design as beneficial to all people must be promoted. Hopefully in the near future it will become routine to design and build all facilities for *all* people.

BIBLIOGRAPHY

Access Chicago: Architect's and Designer's Handbook of Barrier-Free Design. Chicago, Illinois: Access Chicago, Rehabilitation Institute of Chicago.

Accommodations for the Physically Handicapped: VA Construction Standard CD-28. Washington D.C.: Veterans Administration, 1973.

American Society of Landscape Architects Foundation. *Barrier Free Site Design.* Washington, D.C.: U.S. Government Printing Office, 1975.

American Standards Association, Inc. *American Standard Specifications for Making Buildings and Facilities Accessible to, and Usable By, the Physically Handicapped.* Chicago, Illinois: National Society for Crippled Children and Adults, Inc., 1961.

Committee on Barrier Free Design. President's Committee on Employment of the Handicapped. *A Survey of State Laws to Remove Barriers.* Washington, D.C.: The President's

Committee on Employment of the Handicapped, August 1973.

Day On Wheels. Washington, D.C.: Public Buildings Service, General Services Administration, January 1975.

Design for All Americans. A report to the National Commission on Architectural Barriers to Rehabilitation of the Handicapped.

First Report of the Architectural and Transportation Barriers Compliance Board to the Congress of the United States. Washington, D.C.: U.S. Department of Health, Education and Welfare, 1974.

Funding Guide for the Removal of Environmental Barriers. Architectural and Transportation Barriers Compliance Board, Washington, D.C., May 1976.

Funding Sources. National Endowment for the Arts and Educational Facilities Laboratories. New York, N.Y., 1976.

Kliment, Stephen A. *Into the Mainstream: A Syllabus for a Barrier-Free Environment.* Washington, D.C.: American Institute of Architects, 1975.

Minimum Property Standards on Housing for the Elderly, with Special Consideration for the Handicapped, HUD pg. 46. Washington, D.C.: U.S. Government Printing Office, 1971.

National Conference on Housing and the Handicapped. Houston, Texas: Goodwill Press, 1974.

Office of the Secretary, U.S. Department of Transportation. *Travel Barriers.* Washington, D.C.: U.S. Government Printing Office, 1970.

Proceedings of National Conference on Housing and the Handicapped. Bethesda, Maryland: Health and Education Resources, Inc., 1974.

Proposed ANSI A 117.1 "Revisions—State-of-the-Art Draft." Draft report submitted for review, December 10, 1975.

Removing Architectural Barriers: An Illustrated Handbook of Chapter 41 of the 1973 New Mexico Uniform Building Code. Santa Fe, New Mexico: Division of Vocational Rehabilitation, New Mexico Department of Education, 1975.

Report to the Congress by the Comptroller General of the United States: Further Action Needed to Make All Public Buildings Accessible to the Physically Handicapped. Washington, D.C.: General Accounting Office, July 15, 1975.

Report to the President and to the Congress of the United States. Washington, D.C.: Architectural and Transportation Barriers Compliance Board, 1975.

Ruder and Finn, Inc. *Recommendations and Guidelines for a National Public Awareness Effort for Developmental Disabilities.* Chapel Hill, North Carolina: Developmental Disabilities/Technical Assistance System, 1975.

Summary of the Housing and Community Development Act of 1974. Washington, D.C.: U.S. Government Printing Office, 1974.

Syracuse University Research Office, School of Architecture. *Proposed ANSI A117.1 Revisions,* First Research Draft, March 15, 1976. Syracuse, New York.

Thomas, Stanley B., Jr. *Report to the President and to the Congress on Housing Needs of Handicapped Individuals.* Washington, D.C.: Architectural and Transportation Barriers Compliance Board, 1975.

Urban Mass Transportation Act of 1964 and Related Laws. Washington, D.C.: U.S. Department of Transportation, 1974.

TRANSPORTATION ACCESSIBILITY

Awareness Paper Prepared by

Helen F. Goodkin
Consultant
Rehabilitation Institute of Chicago

ACKNOWLEDGMENT

The White House Conference on Handicapped Individuals wishes to thank, for her review of this paper:

Mrs. Kathaleen C. Arneson
Rehabilitation Services Administration
Department of Health, Education and Welfare
Washington, D.C.

TABLE OF CONTENTS

	Page
Introduction	171
Historical Perspective	171
Mobility-Limited Population	171
Legislation—The Right to Travel	171
Mass Transportation and Employment	172
Mass Transit	173
Urban	173
UMTA Regulations	174
Buses	174
Rapid Transit	175
Dial-a-Ride	177
Rural Areas	178
Commuter Railroads	178
Private Vehicles	178
Automobiles	178
Private Bus Services Taxis, and Paratransit	179
Long Distance Transportation	180
Air Travel	180
Amtrak	181
Interstate Buses	182
Ships, Boats, and Ferries	182
Communications	182
Conclusion	183
Bibliography	183

INTRODUCTION

Those of us who remember Christmas of 1973, will probably never forget it. Laced in with Santa Claus, eggnog, and Christmas cookies, were long lines of motorists waiting angrily, often fearfully, at filling stations. The oil embargo made us realize that we were a nation of auto-dependent people, and we couldn't quite believe the situation in which we found ourselves. Rationing, higher taxes, or worst of all, no fuel loomed rather heavily on the holiday horizon.

Each and every minority, and suddenly we had all become a member of some minority, was certain that rationing should not apply to them. Few people gave much thought to driving less and using public transportation more. Yet, between the energy shortage and the pollution crisis, that is the path this country must follow.

There was one group, however, with a legitimate case—those who because of physical or mental disability could not ride on public transportation. For the mobility-limited, driving to work is not a luxury, but a necessity caused by government and private industry's failure to take their needs into account when planning transportation facilities. It is fortunate that the oil embargo was lifted before anyone lost his job or had to quit school. Yet, one can't help wishing for some kind of crisis that would force transportation planners to go beyond the policy statements contained in legislation and take immediate, positive action to provide transportation to all U.S. citizens. Two years after the embargo, the mobility-limited still cannot ride public transportation, and there is no provision to ensure that those who are able to drive an automobile would get gasoline in the event of another energy shortage.

HISTORICAL PERSPECTIVE

Mobility-Limited Population

The mobility-limited population consists of those people who because of some physical or mental handicap have difficulty using public transportation. The handicap may be the result of paralysis, emotional disturbance, neuromuscular or neurological disease, arthritis, stroke, mental retardation, severe pulmonary or cardiac disease, blindness, deafness, amputation, temporary injury, or the natural process of aging. The handicap may necessitate the use of canes, crutches, a walker, a wheelchair, or a prosthesis, or it may simply impair the ability of the person to utilize stairs and heavy doors, walk long distances, or understand the complexities of transit schedules and procedures.

Estimates of the number of persons who suffer from a mobility-limitation that prevents or hinders their use of public transportation range from about 5 million to 44 million, depending on who is counting and how the category is defined. A current, reasonable figure is 13,370,000, which "represents the number of American handicapped (elderly and non-elderly) who suffer transportation dysfunctions." If the 13,036,000 elderly are added to this, the total is 26,406,000 persons who have at least some degree of difficulty utilizing public transportation. These figures were developed by the Transportation Systems Center for a study entitled, "The Handicapped and Elderly Market for Urban Mass Transit," prepared for the Urban Mass Transportation Administration (UMTA), U.S. Department of Transportation.

For these people, steps, escalators, narrow doors, long corridors, and other architectural barriers, as well as poor lighting and signage, represent almost insurmountable obstacles to the use of public transportation. In designing transportation facilities in this country as well as most public buildings, it seems the *average* needs of an individual are considered rather than his *maximum* needs. We expect people to adapt to the physical environment created, rather than the other way around. Yet, when structural, mechanical, or electrical problems are addressed, the maximum foreseeable extremes of performance are paramount. It is time that we begin to view problems of design the way we view problems of structure. The easier public transportation is to use, the more it will be used. Removing barriers helps not only handicapped and elderly persons, but everyone—the man with many packages and the mother with a child in a stroller.

Legislation—The Right to Travel

Congress has been aware of this problem for many years, and several pieces of legislation have been passed to deal with it. The language of these laws is general, and the Department of Transportation (DOT) has been slow to develop specific policies, regulations, and criteria relating to travel for persons who are handicapped and elderly.

There has been almost no enforcement of any of this legislation.

In 1965, Congress formed the National Commission on Architectural Barriers to Rehabilitation of the Disabled. Its report resulted in recommendations that were made effective in 1968 with the passage of the Architectural Barriers Act (P.L. 90–480) which made it incumbent upon the Federal government to ensure that all buildings or facilities financed with Federal funds were designed and constructed to be accessible to physically handicapped persons. The committee report accompanying P.L. 90–480 urges that "the word building as used in this bill be given the broadest possible interpretation and include any structure which must be used by the general public, whether it be small rest station in a public park or a multi-million dollar Federal office building." No specific mention of vehicles or conveyances is made.

Congress continued to press for barrier-free design with the passage in 1970 of the Biaggi amendment (P.L. 91–453) to Section 16 of the Urban Mass Transportation Act of 1964 which made it a "national policy that elderly and handicapped persons have the same rights as other persons to utilize mass transportation facilities and services." This amendment further specifies that not only must "special efforts" be made to provide such facilities and services to elderly and handicapped individuals, but that "all Federal programs offering assistance in the field of mass transportation contain provisions to implement this policy."

The Federal-Aid Highway Act of 1973 (P.L. 93–87) also required that projects funded by the Highway Trust Fund "shall be planned, designed, constructed, and operated to allow effective utilization by elderly or handicapped persons . . . including those who are non-ambulatory wheelchair bound . . . who are unable without special facilities or special planning or design to utilize such facilities . . . ."

The 1974 amendments to the Federal-Aid Highway Act (P.L. 93–643) broadened the intent of Congress even further by stating, "The Secretary [of the Department of Transportation] shall not approve any program or project . . . which does not comply with the provisions of this subsection [subsection (b) of section 165] requiring access to public mass transportation facilities, equipment, and services for elderly or handicapped persons." In addition, the Federal-Aid Highway Act and the National Mass Transportation Assistance Act of 1974 (P.L. 93–503), which will be discussed later, provided for a number of special services and funds to assist handicapped and elderly individuals.

The DOT Appropriations Act of 1975 (P.L. 93–391) specifically directs that "none of the funds provided under this Act shall be available for the purchase of passenger rail or subway cars . . . motor buses, or for the construction of related facilities unless . . . [they] are designed to meet the mass transportation needs of the elderly and handicapped."

The Rehabilitation Act of 1973 did more than provide guidelines and funds for rehabilitation programs operated by the Department of Health, Education and Welfare. This landmark piece of legislation addressed, for the first time, the overall problems of handicapped individuals. In addition to an affirmative action employment policy, it set up the Architectural and Transportation Barriers Compliance Board, which is charged with seeing that the provisions of P.L. 90–480 are adhered to. Made up of representatives of nine Federal governmental agencies, the Board hopes to address itself to a wide variety of barriers problems.

More importantly, however, Section 504 of the Act is the broadest statement, to date, against discrimination of handicapped persons. It states, "No qualified individual in the United States . . . shall solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subject to discrimination under any program or activity receiving Federal financial assistance."

Based partially on Section 504, a suit was brought in 1975, against the Jefferson County Transit Authority, Birmingham, Alabama, by a handicapped person who was unable to board a bus. The Federal District Court Judge said, in part, that the individual was not denied the benefits of the bus since she could ride the bus if carried on and off. An appeal is pending. It is interesting to note that the Urban Mass Transportation Administration does use Section 504 as part of its authority for regulations which have been proposed governing transportation for handicapped and elderly people.

Mass Transportation and Employment

Federal legislative precedents for travel of handicapped individuals have been set largely in the areas of architecture and mass transportation. This does not discount the importance of travel

by airplane, railroad, commercial bus, or boat, but it does reflect the vital link between employment and transportation. According to Dr. Henry B. Betts, Executive Vice-President and Medical Director of the Rehabilitation Institute of Chicago:

> If the millions of dollars spent each year on the rehabilitation of handicapped individuals are to have any meaning, the environment, the community as a whole, must be open to them. They must return to the mainstream of life as quickly as possible; they need a job rather than welfare; they must be socially and economically independent. If the bridge to employment is crossed, almost everything else will fall into place.

Abt Associates, in a study done for DOT in 1969, estimated that 59% of handicapped persons have combined family incomes of less than $3,000 a year and only 10% earn over $10,000. These low income figures are due largely to the inability of the handicapped population to secure employment. While 65.1% of the non-handicapped population (age 17–64) enters the work force, only 47.8% of the handicapped population is employed. Abt Associates also estimates that 67% of unemployed handicapped persons would seek employment if accessible, low cost transportation were available. If these people become part of the work force, minimum yearly economic benefits (total yearly increase in goods and services) of $824,000,000 would result. This figure does not take into account such things as increased income tax revenues or decreased welfare payments, nor does it take into account such unquantifiable factors as increased educational and vocational opportunity, or the social and psychological impact on the handicapped individual.

The Report of the Comprehensive Needs Study of Individuals with the Most Severe Handicaps, mandated by Section 130 of The Rehabilitation Act of 1973, painted an even bleaker picture.

Two sample groups were studied: 1)Patients in a comprehensive medical rehabilitation facility (at the time the study began) and 2)Individuals rejected by Vocational Rehabilitation Placement agencies as too severely disabled. With the first group, transportation was the greatest, single unmet need. A significant number of persons in both groups indicated that transportation was the major reason for not working. Of the rehabilitation group, 45% needed transportation to go to work, and 60% of these did not have it. Of the same group, 71% had to be driven by friends or family; 20% could drive; 11% were homebound primarily because getting in and out of vehicles was impossible. Of the total, 25% spent $11.00 a week on transportation (6% over $76 a week), although only 12% were working at the time.

Economically, the elderly population is not dissimilar from the handicapped population, and it is not surprising that both groups travel about ½ to as much as the general population. For the most part, these are essential trips for medical appointments or shopping. When they do travel, they are generally forced to use high cost taxis (14% of the trips by handicapped persons are by taxi versus 2% for the population as a whole) or are driven by a friend or relative in a private car. Until such time as public transportation is made available to this segment of the population, their isolation will continue.

MASS TRANSIT

Urban

In recent years, mass transit services—bus, rapid transit, and commuter railroad—have come under increasingly heavy economic pressure as costs of maintaining lines and improving services have risen faster than revenues. Almost all significant capital for this purpose must come from Department of Transportation (DOT) funds. Despite legislation, accessibility has not been a major priority of DOT in granting funds. The Urban Mass Transportation Administration (UMTA) in DOT has funded a few research and demonstration projects, but, until very recently, it has exerted little or no pressure on local transit bodies to achieve or even work toward accessibility.

UMTA Regulations

In response to increasing demands for accessibility, both from Congress and the consumer, UMTA began in 1974 to develop regulations for handicapped and elderly transportation service. Hearings were held on the proposed regulations in the spring of 1975, and the final regulations were issued in April, 1976. Under the new regulations, the emphasis is on local planning and the inclusion of "special efforts . . . [for] public mass transportation facilities and services that can

effectively be utilized by elderly and handicapped persons." To meet this requirement, transit authorities must determine the needs of disabled individuals in their service areas and develop ways to meet these needs, depending on local conditions. No specific guidelines are given.

The new regulations require that "every fixed facility—including every station, terminal, building, or other facility—designed, constructed, or altered . . . with UMTA assistance . . . shall be designed, constructed, or altered in accordance with the minimum standards in the 'American Standard Specifications for Making Buildings and Facilities Accessible to, and Usable by, the Physically Handicapped.' " This includes any work relating to "existing stairs, doors, elevators, toilets, entrances, drinking fountains, floors, telephone locations, curbs, parking areas," but existing facilities where "the application of the standards is not structurally possible" are exempt.

All new buses purchased after February 15, 1977 shall have risers of not more than 8 inches, and the distance to the first step may not exceed more than 8 inches from a 6-inch curb. All bus designs must have a wheelchair accessibility "option" (either a lift or a ramp). These, however, are not required.

Rapid rail vehicles shall have doorways with a minimum 32-inch clearance, and "the design of the vehicle shall be coordinated with the boarding platform design [of accessible stations] in order to minimize the gap between the vehicle doorway and the platform."

Because of increasing UMTA interest in light rail vehicles (street cars), specific guidelines for these cars have also been written. Buffalo, New York, is about to develop a new light rail system, and both Boston and San Francisco have light rail vehicles in service at the present time. UMTA had made a grant to Boeing (the designer of current light rail vehicles) to develop a level change device for wheelchair boarding of light rail when it is operating at street level without a platform. Such a device is not now required.

All three types of vehicles are required to have proper lighting, audible and visible information systems, non-skid flooring, accessible fare collection boxes, proper handrails for boarding, and other features to aid the mobility-limited.

The regulations offer only a partial victory for the handicapped persons. Not only are wheelchair-accessible buses not required, but the strong emphasis on "local planning" may permit a transit authority to utilize special, local transit systems rather than to make the main systems available to all. Another potential problem area is the "waiver" clause for remodelling of fixed facilities. UMTA asserts that this will be decided on a case by case basis, but the criteria for these decisions are not known.

Finally, of course, the biggest problem is that UMTA took over two years to finalize these regulations which in final form can hardly be considered a mandate for accessibility. UMTA has, through its long deliberations, clearly thwarted the written intent of Congress, and one can only speculate on how vigorously even these minimal requirements will be enforced.

Buses

The question of available, accessible bus transportation throughout a mass transit system has not yet really been addressed by transit planners. However, with the conclusion of the DOT Transbus program, things are beginning to happen. Transbus was UMTA's research project to develop "the bus of the future" that will contain the first basic changes in urban transit buses in more than 15 years.

In 1971, sub-contracts for this more than $2 million project were made with American General Corporation, GMC Truck and Coach Division, and Rohr Industries to develop their own designs, based on pre-determined criteria. The buses were to be wider and sleeker, with improved heating, lighting, and air conditioning, and capable of speeds of up to 70 miles an hour. They were to have lower floors and smaller steps up into the bus. Each company was to address itself to the question of accessibility for handicapped persons. The buses were tested in 1974, and the new bus was to be developed by 1977.

All the Transbuses had 40-inch doors and space inside to accommodate wheelchairs. The AM General design required a curbside platform and a flat ramp built into the bus which bridges the gap. The bus had a special feature built into the suspension system which allowed the driver to adjust the height of the bus floor to any point between 17 and 20 inches off the ground.

The GM design called for a hydraulic lift which projects from the front step when needed. The Rohr design included the "kneeling" suspension feature found in the AM General bus and a ramp which projected out from under the bus floor and lowered to the curb.

Handicapped groups who tested the buses throughout the country were generally not totally impressed. The ramps were too steep; the lift platforms not wide enough, etc. At least, however, decided technological progress has been made through the Transbus program. The new features are better, if not perfect, and they afford improved access to countless handicapped individuals.

In August, 1976, UMTA published a final statement on Transbus policy, including features that would be required, in the future, on UMTA funded buses: 8 inch steps and effective floor heights of 24 inches or less, after use of a kneeling feature. Wheelchair accessibility features remain optional, and the higher floor height makes level changing devices technically more difficult and more costly. It appears that UMTA did not require a lower Transbus floor (17–20 inches) in part because it did not want to place the financial burden of such a drastic design change on manufacturers.

With this policy statement, UMTA believes that the objectives of Transbus have been met—a more comfortable, more attractive bus will soon be commercially available. However, a coalition of elderly and handicapped consumers, led primarily by the Disabled in Action of Pennsylvania, has brought a Federal suit against UMTA, arguing that the Transbus program has demonstrated that a safe, reliable, full-sized bus can be produced which handicapped persons can board and alight from in regular transit service. They are asking the court to require that "Federal financial assistance be expended only to purchase the lower floor, wide door, ramped Transbus" and that DOT take any other action necessary to ensure accessible mass transportation.

Community action on accessible buses has been slow primarily because, since there has been no concerted demand for them, manufacturers simply have refused to make them. In San Francisco, transit planners have been unable to provide accessible bus transportation to Bay Area Rapid Transit (BART) stations because design specifications for wheelchair accessibility could not be met by manufacturers.

A preliminary court injunction issued in December, 1975, has prevented the Milwaukee County Transit Authority from purchasing new buses because the proposed design was inaccessible. The court has not yet issued a final ruling.

In the Southern California Rapid Transit District (SCRTD) in Los Angeles, the Board of Directors passed a resolution requiring that all buses be accessible and held up purchase until such time as accessible buses could be purchased. Until the Transbus controversy and the UMTA regulations were settled, no company was willing to go into production. Redesigning buses for a limited order was too expensive. In October, 1976, UMTA approved SCRTD's grant application and a bid from AM General for 200 wheelchair accessible buses was accepted. They will begin going into service next year on regular, fixed route service.

Other communities across the country are now in the process of buying new accessible buses or retro-fitting old ones. How the buses will be deployed is often unclear. In the race to get hardware, the planning phase of the UMTA regulations seems to be not well thought out. Adequate service for the disabled may or may not follow.

The paradox is that while there is almost no totally accessible public transportation in this country, Federal legislation now requires that transit providers give handicapped as well as elderly persons reduced fares during non-peak hours (Section 5(m) and Section 108 of P.L. 93–503, The National Mass Transportation Assistance Act of 1974). While this legislation does benefit those handicapped and elderly individuals who can somehow climb up the steps of a bus or negotiate the steps of a rapid transit system, it has become a public relations heyday for transit authorities across the country who have used this to improve their image in the community at large without improving the lot of severely disabled people in any way.

Rapid Transit

In recent years, several major cities have undertaken the building of rapid transit lines; among them are San Francisco, Washington, D.C., and Atlanta. In San Francisco and Washington, accessibility provisions both for stations and rolling stock were forced on transportation officials well after much of the planning and designing had been completed. ANSI specifications regarding wide doors, elevators, accessible fare collection, and wheelchair space inside the cars had to be added after most of the planning and designing had been completed.

The Bay Area Rapid Transit Authority (San Francisco) became the first accessible system only after legislation, passed by the State legislature

and signed by the Governor, required that these provisions as well as accessible restroom facilities be included. The result is an accessible, but not necessarily truly usable system. Long distances must often be travelled to go from the elevator to the entrance gate and from that gate to the boarding platform. Assistance is needed to enter elevators and, in some stations, to go through the turnstiles.

Transit officials nationally have been using BART as an example of why rail transit should not be made accessible. They argue that it cost $10 million to add accessibility features, and to date, ridership by handicapped persons is low. Disabled people are not, they argue, physically able to utilize mass transit; they need the door-to-door service provided by special bus systems. The crowds, rapid door closing, and sometimes jerky motion are "too much" for handicapped persons.

There are, however, several factors to consider. First of all, it takes a long time to wean a person from his car back to rapid transit. This is true of non-disabled persons, but especially true of handicapped individuals who have probably never ridden public transportation at all. It will come in time, particularly as the costs of car maintenance increase. Secondly, the feeder buses serving the BART stations are inaccessible; a handicapped person must either live within a few blocks of a station, or drive or be driven to the station in a private car. Thirdly, BART was designed primarily for commuter travel, thus schedules are not geared for most cultural and recreational trips. Finally, one must keep in mind that San Francisco and the communities around it are inaccessible. Curb ramps are few and far between; most buildings are not accessible. However, any community with a capital investment project of this magnitude must look to the future. BART was not designed for the next ten years, but the next 50 to 75 years. As architectural barriers to disabled persons come down within the community, BART and other rapid transit systems must be prepared to serve the needs of handicapped citizens.

In Washington, D.C.'s Metro system, accessibility features came about after the fact, despite P.L. 91–205 which stated that "construction of the subway stations, entrances, and exits thereto and all other related facilities necessary for this [Metro] system will in fact be subject to the requirements of P.L. 90–480." Metro planners, however, elected to provide accessibility only through the use of escalators, rather than elevators. The planners felt that the increased ridership which elevators would allow did not justify the additional cost.

Washington area consumers brought a suit in 1973; and, in the Fall of that year, a Federal judge ruled that if the stations were not accessible to disabled persons, the system could not be used by the public. This forced Congress to appropriate an additional $65 million to cover what was then the "additional" cost of accessibility. In 1975, the Federal District Court prevented Metro from opening stations that were not yet accessible. One inaccessible station has been opened under a temporary waiver granted by the General Services Administration. The validity of this waiver is being contested by a lawsuit which has been brought.

The problems which concerned Metro planners were not ridership alone, but also security within the elevators and the high cost of maintaining them. (Estimates for maintaining the Metro elevators run as high as $1.25 million annually.) The answers to these problems are more difficult than technology for accessibility. Security can be improved significantly by keeping elevators, escalators, and fare collection in a central core, not spread throughout the system. Both BART and Metro were unable to achieve this throughout their systems because in some stations elevators had to be fitted-in very late in the planning. Maintenance is expensive, but in the long run, cheaper in terms of pollution and energy consumption than private autos.

In Atlanta, where rail service is expected to begin late in 1978, concern for accessibility came about after planning had begun, but before most bids had been issued. As a result of public hearings on reduced fares for persons who are elderly and handicapped, an Elderly and Handicapped Advisory Committee to MARTA (Metropolitan Atlanta Rapid Transit Authority) was formed. This group is reviewing rail planning and design, and recently made a request to MARTA's constituent governments to take positive action to remove architectural barriers to movement outside the transit system.

Atlanta's problem, as with the systems in San Francisco and Washington, D.C., is requiring architects and engineers to go back to their drawings and redesign them in terms of total accessibility. As with the BART and Metro systems, it is possible to comply with the law and still not provide convenient, accessible transportation. The questions that must be addressed are: If

a person with limited stamina must go out of his way to utilize the accessible entrance to a station, have we provided accessible transportation? Will he give up his automobile to relieve inner city congestion or make a trip he would not otherwise make? The answers are "No".

Transportation must be convenient as well as accessible if it is to be utilized by the handicapped or the non-disabled rider. Atlanta has the potential for meeting the needs of handicapped people, partly, because there are two prior systems from which to learn; partly, because of the dialogue which appears to be taking place between consumers and providers.

Even greater problems result in cities where existing rail service is inaccessible. New York, Chicago, and Boston are confronted with the almost overwhelming task of remodeling to provide accessibility. Some existing stations can never be made accessible; others can only be made accessible at great, and perhaps unnecessary, expense to the taxpayer. Most, however, can and should be remodeled.

Chicago's Transit Authority (CTA) is a typical situation. Two proposed extensions of the CTA system and the replacement of the elevated lines in the Loop with a new subway system are planned to be fully accessible. All new rail cars have been ordered with wider doors. While the CTA is going ahead slowly with some remodeling of the existing system, it has done so reluctantly without taking any really active interest in the problems of handicapped persons or receiving input from them.

New York City's subway system remains almost totally inaccessible. Twenty-three stations have elevators, but in some, one must negotiate stairs to reach them. State legislation required that the new Second Avenue line be accessible, but work has been halted because of funding problems.

Among transit planners as a whole, accessible rail systems are generally considered costly and unnecessary, and accessible urban transit buses unthinkable. According to planners, elevators, especially in underground systems, are costly to build and expensive to maintain and present a safety hazard. Many planners express concern for how the "patients" will tolerate the high-speed trains and how they will move through crowds and electrically controlled doors. They demonstrate a type of naivete about the capabilities of the mobility-limited who are not patients, but healthy, medically stable individuals who have difficulty walking, using their arms, negotiating stairs, or riding high speed escalators.

Dial-a-Ride

Most planners, it would appear, prefer transporting elderly and handicapped persons on special, demand responsive, door-to-door bus services, equipped with lifts or ramps. This service attempts to combine the door-to-door convenience of the taxi with the economic value of a bus. Where no other public transportation services exist (suburban and rural areas), demand responsive systems serve a need for those unable physically, mentally or financially to operate an automobile. In cities where public transportation services exist, demand responsive systems are necessary only until existing services can be made accessible.

The need for transportation among the handicapped is so great that social service agencies, hospitals, and other community groups have started a variety of individualized non-profit bus services in communities throughout the country. Several municipal governments and transportation authorities have also begun systems for elderly and handicapped persons using revenue sharing money and, in some cases, DOT demonstration funds and funds from the Older Americans Act.

Vans especially equipped with hydraulic lifts, locking devices for wheelchairs, and specially trained drivers are required for this service. In addition, routing of buses is time consuming and tedious, particularly if the system is completely demand-responsive and door-to-door. Fixed route systems operating between certain points in communities are obviously more efficient than systems which operate more like a taxi service. Recognizing the tremendous costs involved in programs such as these, the Federal-Aid Highway Act of 1973 has made capital funds available to non-profit corporations to purchase accessible vehicles.

The Department of Transportation has also funded a program for the development of requirements, concepts, and specifications for a "small bus" which could be utilized in dial-a-ride services.

Dial-a-ride services of all types currently have estimated gross operating costs of $1.17 per mile, of that 81¢ per mile is subsidized and revenues provide 22¢ per mile. Cities offering the services must absorb an average cost of 14¢ per mile.

Experts anticipate this cost rising to 60¢ a mile or more. A fleet of 25 to 50 buses, working 10 hours a day, would cost between $700,000 and $1.8 million annually and would accommodate a city of 100,000 covering a 20 square mile area. Transit authorities argue that superior service, not cost, is the key factor in providing public transportation. Although it provides moderately priced and effective transportation, dial-a-ride still exceeds the budgets of most of the handicapped and elderly people it is to serve. The dial-a-ride systems which are successful are those with a large ridership utilizing third party payers. Several programs which began with Federal subsidy were forced to close down after Federal support was withdrawn because of the gap between revenues and operating costs.

Dial-a-ride systems cannot operate without large operating subsidies. Many handicapped consumers feel that if transit planners are allowed to provide only dial-a-ride services, as transportation funds become tighter and tighter, these small special systems will be the first to go.

Moreover, if the goal for handicapped and elderly persons is to bring them into the mainstream of American life, can a separate-but-equal system be condoned which does not allow the mobility-limited individual to function under the same circumstances as the non-disabled person? Handicapped consumers argue that they do not want a separate system. They have the same rights to transportation as they have to police protection, education, and other public services.

Rural Areas

Even though 56% of handicapped and elderly citizens live in urban areas, mention must be made of the specialized transportation problems of the mobility-limited residents of rural areas where practically the only mode of transportation is the private car. Elderly people are particularly vulnerable in these areas. As they become older, they are no longer able to work the farm or even continue to live there. Their children have moved away and so they come to live in elderly housing "in town". Not only is this a new experience for them, but if community transportation services do not exist, it is a very limiting one.

Recognizing this need, the Federal-Aid Highway Act of 1973, as amended, authorized the appropriation of $75 million for a two-year program of demonstration projects for public mass transportation in rural areas. This program is jointly administered by two agencies in DOT, the Federal Highway Administration and UMTA. DOT recognizes the need for such programs to be adaptable to the needs of handicapped and elderly people, both in terms of accessibility and travel requirements.

Commuter Railroads

Little is being done in terms of accessibility by the private companies which own commuter railroads. Stations and other fixed facilities are old and inaccessible, and a handicapped person cannot rely on the system to bring him from his suburban home to his job downtown. In many parts of the country, this may limit severely his choice of community and will certainly make him totally auto dependent. Neither UMTA nor the Federal Railroad Administration has prioritized commuter railroad transportation, and consumer action is needed if change is to occur.

PRIVATE VEHICLES

Automobiles

The public transportation picture is generally so bleak that most handicapped persons travel by private car which assumes they are able to drive and can afford to buy and maintain automobiles or vans. If they cannot, they must depend on the good-will and generosity of friends and family, a difficult situation at best.

The problems of car ownership are many, especially for the urban resident. In addition to the cost of gasoline, maintenance, and insurance (which in many states is higher for handicapped drivers than non-handicapped), the cost and hassle of finding accessible parking is enormous. In Chicago, for example, it is not unusual for a person employed in the Loop to spend $100 a month on parking, which includes a minimum of $35 in a garage at his apartment, $45 at work, plus special parking fees for trips to shopping, movies, theatre, etc. A person, disabled or not, has to have a fairly good job to support such expense. In suburban and rural areas, parking is generally free, but the accessibility problem remains. All too often handicapped persons find that a street curb prevents them from getting out of their cars, or a step up to an elevator prevents them from using a parking garage.

The greatest expense, however, is the initial purchase of an automobile or van. If the individual owns a car before he becomes disabled, it is not difficult or costly to convert it to hand controls. If, however, a newly handicapped person must purchase a car or van before he can start employment, he or his family needs substantial financial resources. This expense may come after many months of costly hospitalization and rehabilitation therapy and is often a larger financial burden than the individual can afford. In addition, compact, more economical cars are too small to accommodate wheelchairs which forces individuals in wheelchairs to purchase larger, higher priced models which consume more gasoline. If a person is unable to transfer or uses an electric wheelchair, he must use a van equipped not only with handcontrols, but also a hydraulic lift. This can cost as much as $8,000.

The whole area of vehicle design needs to be carefully examined with a view toward improved accessibility for persons experiencing all types of mobility-limitations.

Many states and municipalities have begun to address themselves to the problem of parking for handicapped citizens. Many state architectural barriers laws include provisions for wheechair parking stalls in lots and garages. These stalls require an additional five foot space for unloading a wheelchair as well as level access from the space to adjacent facilities. In addition, many states are issuing license plates with the barrier-free symbol to handicapped drivers. Any car bearing these plates is given special parking privileges which allow it to park in areas where parking is generally prohibited and to let the meter run out.

To assist the disabled driver as well as the wheelchair pedestrian, the Federal-Aid Highway Act (P.L. 93–87) requires that all streets constructed with Federal funds provide curb cuts or ramps for physically handicapped persons, including those in wheelchairs. This means that ramps must be constructed at intersections to allow a person in a wheelchair to cross the street. Many states and towns have also passed legislation requiring that all new or replacement curbs be constructed with a ramp.

The problem of insurance is another area which is beginning to be addressed by state governments. Legislation must be passed to prohibit an insurance company from charging a handicapped person a higher rate and to prohibit insurance companies from refusing to insure a handicapped driver because of his handicap. The record indicates that handicapped drivers are average risks, with no more traffic convictions than non-disabled people.

Driver education programs for handicapped people are increasingly available throughout the country, and most states license handicapped drivers except those who have severe visual problems or neurological impairment. Another exception is that in many states, persons who have been institutionalized for an emotional disturbance are denied driver's licenses. A study of licensure procedures for handicapped drivers has been funded jointly by DOT and the Bureau of Education of the Handicapped (HEW). The Department of Transportation has also supported a number of research programs relating to driver education for handicapped persons, primarily through The National Highway Traffic Safety Administration. Special emphasis has been placed on deaf and mentally retarded drivers.

Several pieces of Federal legislation have addressed the problem of the additional expenses incurred by handicapped persons who must maintain an automobile because accessible public transportation is not available to them. In every session of Congress several bills are introduced which provide tax credits or deductions for employment related transportation expenses of handicapped individuals. Unfortunately, these bills are never passed. Moreover, they are only beneficial to the handicapped person who is working and paying taxes. The person on low income or the person on welfare who still has transportation requirements is not assisted by tax incentives.

The larger problem of assistance for the purchase of an automobile has not been discussed in the Congress. The Veterans Administration has set a precedent for Federal assistance in this area by granting up to $3,300 for the purchase of a car and equipping it with hand controls. Either direct grants through the state Vocational Rehabilitation office or a Federal loan program for automobile purchase by those individuals about to become employed would give many persons the first chance at a job. At least one state, Massachusetts, exempts handicapped drivers from paying sales tax on automobile purchases.

Private Bus Services, Taxis, and Paratransit

Most large communities now have a private bus company that provides accessible transportation to persons in wheelchairs. Generally, these com-

panies utilize vans similar to those used by the dial-a-ride services run by transit districts and not-for-profit corporations. Handicabs in Milwaukee is probably the most famous of these services, but by no means the only one.

The problem with these services is the expense. It is not unusual for a round trip to cost as much as $8 to $10. Companies which are operating profitably for the owners rely on servicing clients of third party payers. Handicapped persons who pay their own bills utilize these services only for absolute necessities such as medical and therapy appointments. Only a few utilize them for job related travel or recreation.

In some areas, taxis provide service for handicapped individuals, again at substantial expense. The problems with taxi travel are two-fold: 1) now that most cabs no longer have the larger back seat, it is extremely difficult to make a transfer into the back seat and many communities forbid passengers to ride in the front; 2) cab drivers are generally reluctant to take the necessary time for a handicapped person to get into and out of a taxi. Often the only method of obtaining taxi service is to call and order one by phone; hailing a taxi on the street from a chair is generally ineffective because drivers refuse to stop. Checker Cab Manufacturing Co. has a vehicle which can accommodate wheelchairs, but it is rarely used. The taxi, designed several years ago at the Pratt Institute, will accommodate both wheelchair and ambulatory passengers, but it has never been put into production. DOT has funded a project to develop a "low-pollution paratransit vehicle that is suitable for taxi service." The contract provided for not only the design of the vehicle, but also for the production of one model vehicle which would accommodate ambulatory and wheelchair passengers. These vehicles were displayed this summer at the Museum of Modern Art in New York City. They are, however, intended to provide new design concepts rather than for volume production of paratransit vehicles.

In October, 1976, UMTA published a Proposed Policy Statement on Paratransit Services both in the public and private sector. Federal funds may be made available under Sections 3 and 5 of the Urban Mass Transportation Act of 1964, as amended, for the acquisition of equipment and for the payment of operating expenses. Services which qualify include "dial-a-ride, jitney, community mini-bus, subscription bus service, certain forms of van-pooling, and other types of collective transportation service . . . available to the public." Private cabs are not included.

How long it will take to get an accessible taxi or van on the streets at a price people can afford is anyone's guess.

LONG DISTANCE TRANSPORTATION

Air Travel

Air travel remains difficult for the handicapped individual, even though persons in wheelchairs have flown literally hundreds of thousands of miles without incident. Back in the late 1930's, United Airlines was the first commercial airline to allow a blind person to fly accompanied by a seeing eye dog. Following the Second World War, United was among the first of the major airlines to assist disabled veterans to utilize air transportation. Fork lift trucks were used to load wheelchair passengers. Since that time, handicapped persons have flown so successfully that even though tariff regulations continue to require that a handicapped individual be accompanied by a non-disabled attendant, United and most other major airlines ignore this provision.

The problem, however, lies in the fact that the Captain, not airline administrative personnel, has the right to determine who is and is not able to fly.* Thus, a handicapped person never actually knows what airline policy will be until he gets to the plane. This is particularly acute when a trip requires a change of plane and/or airline before the final destination is reached. This uncertain policy creates the potential for being stranded mid-trip. There have been several suits brought against major airlines by individuals in wheelchairs who, at the last moment, were not allowed to fly. Most have been settled out of court.

In June, 1973, the Federal Aviation Administration issued a Notice of Proposed Rule Making, directed toward amending the criteria for transporting handicapped persons on civil air carriers. Hearings were held in the fall of 1973, and proposed regulations were issued in July 1974.

*The airlines establish their policy and rules or regulations based on their tariffs filed with the Civil Aeronautics Board (CAB). The pilot in command of an aircraft is directly responsible for, and is the final authority as to, the operation of that aircraft. Therefore, if, in the pilot's opinion, the carriage of a handicapped person compromises safety, the pilot has the authority to deny that person passage.

Comments on these proposed regulations were about 90% negative and the FAA is not planning to issue them. Instead, the FAA plans to issue an Advisory Circular to airline companies and airport staff regarding handicapped air travel. This circular has been pending for almost a year, and still no definite date for its release is available.

The FAA regulations, as proposed, required that a handicapped person be permitted to fly if he presents a medical certificate dated within the preceding six months stating that he does not need assistance to evacuate the plane, or is accompanied by a non-handicapped attendant. Blind and deaf persons would be exempt, but few other guidelines on the types of disabilities which would be medically certified were given. In addition, the total number of handicapped persons per flight was limited and the number and location of seats to which they could be assigned was restricted.

Representatives of flight crews have testified at FAA hearings that travel by handicapped persons be restricted because of fear that disabled people will impede evacuation of non-disabled travellers in the event of a crash, and because of concern for the safety of handicapped passengers. Since there was very little data available on evacuating handicapped people, the FAA conducted tests at the Flight Standards Technical Division in Oklahoma City on plane evacuation procedures, initially utilizing dummies and, more recently, with handicapped individuals. The tests reportedly indicate that severely disabled people could be evacuated safely through those exits with chutes, without risk to themselves or others. The final statement from the FAA will reflect the results of these tests.

Meanwhile, handicapped individuals continue to experience difficulty with air carriers. Their business and personal lives can be altered dramatically almost at the whim of flight personnel who are not trained to recognize individual disabilities or capabilities. The FAA must recognize that air travel by handicapped persons presents no unnecessary risks to their safety or that of other passengers, and must adopt regulations that will not infringe on the rights of handicapped citizens. Legislation introduced in the last session of Congress, which would have amended the Federal Aviation Act to provide that no physically handicapped person shall be denied air transportation because of his handicap, did not pass.

Of even greater importance than the regulations is the need for the FAA, the airline industry, and airplane manufacturers to address the question of improved accessibility and improved safety in airplane design. At no time during the discussions of the regulations for air travel by handicapped persons has the question of changing airplane evacuation equipment or procedures been addressed.

While the airlines are "dragging their feet," airport operators are making big strides forward in an effort to remove barriers from air terminals across the country. The Airport Operators Council International, in conjunction with the Architectural and Transportation Barriers Compliance Board, surveyed every airport across the country to determine its accessibility and has compiled a booklet called, "ACCESS TRAVEL: A Guide to Accessibility of Airport Terminals." The booklet gives complete and accurate information on accessibility at airports throughout the country. It is hoped that this information can soon be included in the Monthly Official Airline Guide so that reservation clerks can provide additional assistance to handicapped travellers. Airport authorities are also beginning to develop guides to their facilities, such as the one for Chicago's O'Hare Airport, and at least one airline, TWA, has a booklet for the handicapped traveller.

Amtrak

While there are few visible signs of accessibility on Amtrak, a change appears to be in the wind. It has been Amtrak's *policy* almost since its inception to accommodate elderly and handicapped persons, and the Amtrak Improvement Act of 1973 (P.L. 93–146) reiterated this position, to the extent that financial resources permit. As stated in the Act, Amtrak is to give consideration to the design and procurement of special equipment and facilities, the provision of special training for its employees, and elimination of existing barriers from its facilities.

Although 88% of Amtrak's fleet was built prior to 1950, and the costs of remodeling this equipment are extremely expensive, some new equipment has been placed into service. However, when handicapped persons tested the first of the new cars in early 1975, they found that the aisles were 20-inches wide and the restroom doors only 19-inches wide. Meeting with consumers followed, and Amtrak agreed that all of the new Amcafe and Amclub cars be accessible with 30-

inch aisles and accessible restrooms. New designs for coach cars will have wider aisles. This represents some significant work in terms of changes in railroad car design. The new Turboliner trains running in New York State and a few other locations are accessible. Amtrak plans to expand this service in 1977 so that there is one accessible car on trains at various locations throughout the country.

In addition, Amtrak is in the process of making some stations accessible, either by building new stations without stairs and accessible restrooms or through remodeling in compliance with the ANSI standards. To date, there are six new or remodeled fully accessible stations. New bi-level long distance cars will be accessible on the first level only; they will, however, provide coach and sleeping accommodations, restrooms, and food service. Reservations may now be made on the phone by deaf persons with teletypewriting equipment. A prime mover in this drive for accessibility is the Interstate Commerce Commission (ICC). Its statement, "Decision on the Adequacy of Intercity Rail Passenger Service," while praising Amtrak for what it has done to serve the mobility-limited, makes very specific requests for improved service which should be put into effect in the next several years.

Interstate Buses

In many sections of the country, interstate buses represent the only means of commercial public transportation and, in most cases, it is the least expensive mode. Concern for the rights of handicapped passengers prompted the Interstate Commerce Commission to include a section on travel by handicapped persons in its Notice of Proposed Rule Making issued in June, 1975. This section would require commercial carriers to provide assistance in boarding for handicapped passengers; to allow seeing eye dogs to travel free of charge; and to require that all newly-built or remodeled terminals, including restroom facilities, be designed to accommodate handicapped individuals. The Commission's efforts to codify these rights of the handicapped bus traveller should be applauded, but these efforts must be extended into the area of bus design so that "assistance" would not be the key word, because buses of the future should be fully accessible by law.

It is interesting to note that shortly after these proposed regulations were issued, one of the two largest commercial carriers, Greyhound, began to offer (amidst a flurry of national press) its "Helping Hand Service for the Handicapped." Under this program, Greyhound allows a handicapped person and his attendant to travel anywhere in the United States for the price of one. A doctor's certificate must be obtained. The wheelchair or any walking device is carried free. This, in effect, gets Greyhound "off the hook." The attendant must be able to help the handicapped person board and utilize station facilities, thus alleviating the friction between the corporation and its drivers over who is responsible for assisting disabled individuals during their trip.

Trailways has adopted a similar policy, and both companies say that if you do not have an attendant, "someone" will help you on and off. It could be several months before ICC regulations are finalized and, even then, little improvement will be seen until wheelchair accessible buses are designed, manufactured, and put into operation.

Ships, Boats, and Ferries

Travel by water is becoming less important in this country, and thus not really a burning issue in terms of accessibility. Large ocean liners have elevators, but door widths vary from ship to ship. A person confined to a wheelchair would also find that he might have limited access to a ship's facilities because door widths vary within a ship according to use. Cabin facilities might also be cramped.

Ferries, on the other hand, do provide needed transportation in certain parts of the United States. The Urban Mass Transportation Administration will provide funds for their purchase. Generally, the main deck of a ferry boat is accessible, but upper and lower decks are not. Terminals should also be made accessible.

COMMUNICATIONS

Special attention must be given in all areas of transportation to the problem of communicating information to all passengers. This is particularly important to persons who are blind, deaf, developmentally disabled, and elderly, who are almost totally dependent on public transportation. Such information benefits everyone who must utilize the system.

Blind persons require audible signals for the signs which other people read. Stops, arrivals, and departures must be announced clearly and

distinctly and in sufficient time for handicapped persons to reach an exit door or catch a plane. Elevators should have bells or buzzers, in addition to lights, to announce their arrival. Braille maps and travel information brochures are helpful to those who read Braille. Doorsigns should have raised lettering. For the partially sighted, it is important that signs be in bold colors set one against the other in large bold face type so that they can be distinguished readily.

Some deaf individuals are able to drive an automobile, but many rely solely on public transportation. For these people, clear, accurate, well located signs are necessary. In addition, all warning bells must be accompanied by flashing lights or signals to alert deaf persons to danger.

Persons who are developmentally disabled (i.e., those with cerebral palsy, epilepsy, autism, dyslexia, or mental retardation) generally have difficulty obtaining drivers' licenses and must, therefore, depend on public transportation more than the general population. Reading may be a problem for mentally retarded persons; the use of symbols for exits, entrances, restrooms, loading platforms, restaurants, etc., and color coding for bus and subway lines is most helpful. This will also assist the non-English speaking person whose usage of a transportation system is clearly affected by the language barrier. In planning a communications network for a public transportation facility, some thought should also be given to the person in a wheelchair or a person of a particularly small stature who views signs from a different level than the non-disabled adult. Signage should not necessarily be lowered, but it should be located in such a way as to be easily read from a variety of different levels and locations.

While these recommendations for signage and communication benefit mobility-limited groups directly, they will also assist all persons who utilize transportation systems.

CONCLUSION

In 1972, Congressman Mario Biaggi spoke to the "Conference on Transportation and Human Needs in the 70's"

> [The costs of meeting the transportation needs of disabled persons] cannot be discarded as fringe expenditures when a cost-cut occurs. They have an equal right to use the systems and should have it as a matter of course.
>
> Transit authorities have turned over authority in this area to specialized agencies servicing only the elderly and handicapped. This is certainly not being responsive to the letter or spirit of Section 16. As I see it, though, the people have the great responsibility to implement by amendment and initiate the pressure for reform.

Six years after the passage of Section 16 of the UMTA Act (Biaggi Amendment), the consumer must still remain vigilant. The battle for accessibility, indeed, transportation in almost any form, has only begun. Little progress in terms of facilities built or vehicles purchased has been made. There is, however, a softening of opinion at UMTA, FAA and Amtrak. What was unthinkable a few years ago is now at least discussed. Progress by the transportation industry has been slow, but a base has been built by consumers and consumer groups across the country upon which we can continue to build an accessible nation for our third century. This nation must provide its mobility-limited citizens the same opportunities as non-disabled persons in employment, in recreation, in housing, but most of all, in transportation.

BIBLIOGRAPHY

(The following is a partial list of sources consulted by the author which may be of interest to those seeking additional information.)

ABT Associates, Inc., *Transportation Needs of the Handicapped,* Report to the U.S. Department of Transportation, Cambridge, Massachusetts 1969.

Accent on Living, Summer, 1975, "Transportation for the Disabled," Bloomington, Illinois.

ACCESS CHICAGO, *Toward a Barrier-Free Environment,* Proceedings of the Conference, December 12, 1972, Rehabilitation Institute of Chicago.

American Institute of Architects. Potomac Valley Chapter. *Barrier Free Rapid Transit;* Final Report of the American Institute of Architects to U.S. Social and Rehabilitation Services Administration for the President's Committee on Employment of the Handicapped. Silver Spring, Maryland, 1969.

Booz-Allen Applied Research, Report of the Group, *Provisions for the Elderly and Handi-*

capped in the Design of Transbus, Washington D.C.

Finesilver, Sherman C. *A Study on Driving Records, Licensing Requirements and Insurability of Physically Impaired Drivers.* Denver, Colorado, University of Denver, College of Law, Oct 1., 1970.

Little, Arthur D., Inc., *Employment, Transportation and the Handicapped,* Report to the U.S. Department of Health, Education and Welfare, Washington, D.C.: 1968.

Lundberg, Barry D. and Lustig, Charles W., *Demand Responsive Transit Service: A New Transportation Tool,* Planning Advisory Service, American Society of Planning Officials, Chicago, 1972.

Meisenholder, G.W., "The Case for a Dial-a-Ride", *Proceedings of the Greater Los Angeles Area Transportation Symposia,* 1972–1973.

National Center for Law and the Handicapped, "Accessible Transportation: Will We Get There From Here", *Amicus* Vol. 1 No. 2, Jan., 1976.

National Urban League, *Transportation for the Elderly and Handicapped,* Report to the Urban Mass Transit Administration, Washington, D.C., 1973.

Raggio, James J., Lipman, Benjamin G., Gilhool, Thomas K., and Wolf, Edwin D., *Equal Access to Public Transportation: the Disabled and the Elderly,* Public Interest Law Center of Philadelphia, September, 1975.

Schleichkorn, Jacob S., *Carriage of the Physically Handicapped on Domestic and International Airlines: A Report on the Policies, Rules and Regulations Affecting Travel of the Handicapped.* United Cerebral Palsy Association, New York, 1972.

U.S. Congress. House. Committee on Public Works. Subcommittee on Public Buildings and Grounds. *Design and Construction of Federal Facilities to be Accessible to the Physically Handicapped: Hearings,* Dec. 9, 1969, on H.R. 14464. 91st Congress, first session, 1970. (Com Pub. No. 91–23)

U.S. Congress. House. Committee on Public Works. Subcommittee on Public Buildings and Grounds. *To Consider Accommodations for Handicapped on Metro System (District of Columbia): Hearings,* Jun 29, 1972. 92nd Congress, second session. (Com Pub. No. 92–43).

U.S. Congress. Senate. Committee on Public Works. *Accessibility To Physically Handicapped of Certain Public Facilities.* Report No. 91–658 to accompany H.R. 14464. 91st Congress, second session, Feb 6, 1970.

U.S. Congress. Senate. Special Committee on Aging. *A Barrier-Free Environment for the Elderly and the Handicapped: Hearings,* Pts. 1–3, Oct 18–20, 1971. 92nd Congress, first session, Washington, D.C., U.S. Government Printing Office, 1972, 3 pts., 207 pp.

U.S. Congress. Senate. Special Committee on Aging. *Older Americans and Transportation: A Crisis in Mobility.* Report No. 91–1520, Dec. 1970. 91st Congress, second session, Washington, D.C., U.S. Government Printing Office, 1974, 4 parts.

U.S. Congress. Senate. Special Committee on Aging. *Transportation and the Elderly: Problems and Progress: Hearings,* Pts. 1–4, Feb 25–28 and Apr 9, 1974. 93rd Congress, second session, Washington, D.C., U.S. Government Printing Office, 1974.

U.S. Department of Transportation, Urban Mass Transportation Administration, *Proceedings of the Conference on Transportation and Human Needs in the 70's,* June 19–21, 1972, American University, Washington, D.C.

U.S. Department of Transportation, Urban Mass Transportation Administration, *Public Transportation for the Elderly and the Handicapped,* Washington, D.C., 1971.

U.S. Department of Transportation, Office of the Secretary, *Travel Barriers,* Washington, D.C., May 1970.

U.S. Department of Transportation, Transportation System Center and Urban Mass Transportation Administration, *The Handicapped and Elderly Market for Urban Mass Transit, Executive Summary,* Washington, D.C., July 1973.

U.S. Department of Transportation, Transportation Systems Center and Urban Mass Transportation Administration, *The Handicapped and Elderly Market for Urban Mass Transit,* Washington, D.C.

U.S. President's Committee on Employment of the Handicapped, *Designing Public Transportation for Use by the Handicapped,* Edward H. Noakes. Reprinted from *Performance,* monthly publication of the Committee, Washington, D.C., U.S. Government Printing Office, 1969.

White House Conference on Aging, 1971. *Transportation: Background,* (by) Joseph S. Revis; *Issues,* (by) the Technical Committee on Transportation with the collaboration of the author. Thomas C. Morrill, Chairman, Washington,

D.C., U.S. Government Printing Office, March 1971.

OTHER SUGGESTED BIBLIOGRAPHIES

U.S. Department of Transportation, Office of Administrative Operations, *Transportation for the Handicapped,* Selected References, Bibliographic List No. 8, Annotated, Washington, D.C., April, 1975.

U.S. Department of Transportation, Urban Mass Transportation Administration, *Transportation for the Elderly,* bibliography by Patricia Cass.

U.S. Department of Transportation, Urban Mass Transportation Administration, *Transportation for the Handicapped,* bibliography by Patricia Cass.

COMMUNICATION: TECHNIQUES, SYSTEMS, DEVICES

Awareness Paper Prepared By

Dr. Patricia A. Scherer
Northwestern University
Evanston, Illinois

TABLE OF CONTENTS

Page

Definition 189

Mass Media 190

- Television 190
- Radio 192
- Films and Specialized Materials 192
- Newspapers, Magazines and Journals 193

Telecommunication Systems 193

- Telephones 193
- Teletype Systems 193

Communication Systems In Public Gathering Places 194

- Public Buildings 194
- Public Transportation 195

Graphics 196

- Pictographs 196
- Books, Advertisements and Other Printed Materials 196

Interpersonal Communication 197

- The Family 197
- Service Providers 197
- Readers for Blind Persons 198
- Interpreters for Deaf Persons 198
- Legal Interpreters 198

Sensory Aids For Handicapped Persons 199

- Aids for Visually Impaired Persons 199
- Aids for Partially Sighted Persons 199
- Aids for Blind Persons 200
- Aids for Hearing Impaired Persons 201
- Aids for Deaf-Blind Persons 201
- Aids for Other Physically Handicapped Persons 201

Conclusion 202

Bibliography 202

DEFINITION

Communication is an act of transmission whereby ideas, information, thoughts and feelings are exchanged. It has frequently been defined as one of the prime characteristics of the human being. It is the method through which individuals interact with one another in order that they might adapt to their environment and achieve successful independent living. Human communication can be defined as a complex series of acts which encompasses the ability to receive, process and send an arbitrarily established code.

There are a variety of kinds of communication, all of which are designed to assist individuals in the educational and socialization process. This paper will deal with three major types of communication systems: mass communication, social communciation and electronic and/or mechanical commication.

Mass communication can be viewed as a medium for socio-political purposes. Journalism, radio, T.V. and movies can all be utilized to inform the public of local, national and international events; to influence individuals concerning specific political views; to mold images; and to provide aesthetic experiences.

Social communication is a more personal type of communication between individuals and among groups. It is through this type of communication that the child acquires the language of his culture in order that he might learn to effectively manipulate his environment and lead a productive, independent adult life. Also achieved through this communication is the interaction between persons that permits socialization and the satisfaction of emotional needs common to all people.

In this paper, communication through electronic or mechanical modes is viewed as a means of facilitating or enhancing social communication or mass communication. In this category are such devices as the telephone, teletype, sensory aids, etc.

Within our society today, a handicapped individual frequently finds himself unable to participate fully in the culture in which he lives. A communication deficit is often one of the major causes of his inability to obtain the benefits and rights taken for granted by most non-handicapped individuals.

In order to fully participate in society or to exercise one's rights as a citizen, an individual must be able to communicate effectively with his environment (i.e., he must send information to and receive information from the environment). Thus, when communication is blocked, the eventual outcome is devastating in that human rights basic to the American heritage are denied and the individual is prevented from attaining his full potential. Communication barriers can, therefore, be defined as any object or situation which restricts the free flow of communication and, thereby, denies the handicapped individual full participation in society.

Most handicapped people experience communication barriers in one form or another. For example, attitudes within society are often unfavorable to the handicapped individual. When negative attitudes are communicated to handicapped persons they hinder the development of positive feelings of self-worth. Society maintains these negative attitudes toward differences, partly because the communication systems available to us have not been used effectively to change societal attitudes and behaviors.

Within our society most information is transmitted through visual or auditory channels. Therefore, individuals with sensory handicaps are particularly burdened by severe communication problems. Blind individuals are affected when the communication is exclusively of a visual nature. Mobility is severely restricted because orientation on transportation vehicles and on foot is maintained by visual cues (i.e., street signs, building signs, bus signs, etc). Any public information given only in visual form creates a communication barrier for the visually impaired person and, thereby, reduces his ability to function in an independent manner.

The deaf individual frequently lives in an isolation often not penetrated by society even for purposes of communicating life saving messages. Interpersonal relationships are often severely restricted, resulting in impoverished language which in turn prevents the development of adequate educational, social, recreational, cultural and vocational skills.

Handicaps other than sensory deprivation also impose communication barriers. The individual with severe reading disabilities who is often at a disadvantage in following the complex printed directions in many public facilities; the physically handicapped person in a wheelchair who cannot have access to public gatherings and is, therefore, denied the communication that occurs in such meetings; the child with severe

cerebral palsy who cannot acquire intelligible speech to communicate his basic needs; these are but a few of the common examples of the communication problems which exist in our society today.

Communication barriers are multiple and can be illustrated schematically as indicated in Figure 1.

MASS MEDIA

The mass media (i.e., radio, television, films, magazines and newspapers) has two major responsibilities to uphold in meeting the needs of handicapped individuals in our society. First, it is critically important that the mass media accept the challenge to enhance public awareness concerning the actual effects of handicapping conditions on individuals. Frequently, the handicapped person is portrayed by the mass media as an object of pity or, at the other extreme, as an individual who has totally overcome his problems. Neither of these portrayals provides an accurate picture of the day-to-day accomplishments or day-to-day problems faced by the handicapped person and, therefore, does little to assist the general public in achieving an understanding and acceptance of all handicapped individuals. Therefore, it is important that the information provided to the public be accurate and realistic in order that biases and prejudices that grow out of ignorance can be effectively reduced.

Secondly, the mass media must provide an equality of service for all its constituency. Most individuals in our society today have at their fingertips a variety of ways to inform themselves about important events, both foreign and domestic, to enhance their knowledge about a specific field of interest, or to simply relax and be entertained. The question must be raised as to how effectively these same services reach the handicapped individual. To exclude the individual from these benefits severely impacts on the educational and socialization process, thereby reducing the individual's overall ability to function in society.

Television

The television industry, in the past few years, has made increasingly frequent attempts to inform the public about the effects of handicapping conditions and to promote a positive image of the handicapped person as a contributing member of society. However, these attempts have lacked coordination and have been far too infrequent. A few public T.V. shows such as *Mr. Rogers' Neighborhood and Sesame Street* have made specific efforts to incorporate handicapped persons into their format. Capitol Cities Television Production Studios has become interested in raising the consciousness level of the public concerning handicapping conditions by producing shows which present symptoms of disorders and a possible course of action for obtaining professional assistance when a handicapping condition is suspected. These shows have been well received and Capitol Cities received a national award from the Association for Children with Learning Disabilities for making available to the public a movie version of its hour long show on learning disabilities entitled, "Why Can't I Learn?"

A concerted effort by the mass media is needed to change the general public's attitude toward disabled persons to the extent that behavior is changed and prejudice and bias is reduced.

Of all handicapped individuals, hearing impaired persons are most severely affected by current practices in television. The severe communication deficit they experience precludes them from understanding fully the audio or visual track of television. This is because the visual track does not communicate the same message as the audio track. The program format usually relies on the audio track to interpret the visual track, thereby preventing the hearing impaired person from receiving information from the television or being entertained in a manner similar to that of a hearing person. Some experimentation has occurred throughout the country in an attempt to provide some news broadcasts to the hearing impaired community. In some instances, these efforts have succeeded in providing an interpreter during the news broadcasts while others have utilized the technique of written captions. One of the most successful of these efforts has been the captioning of the ABC Evening News when it is rebroadcast on the Public Broadcasting Service.

When the individual is unable to receive information from T.V. or radio there are life saving consequences in that emergency warnings are not communicated. Currently, the Federal Communication Commission (FCC) has proposed two major rulings to assist in the resolution of this problem. In response to a petition

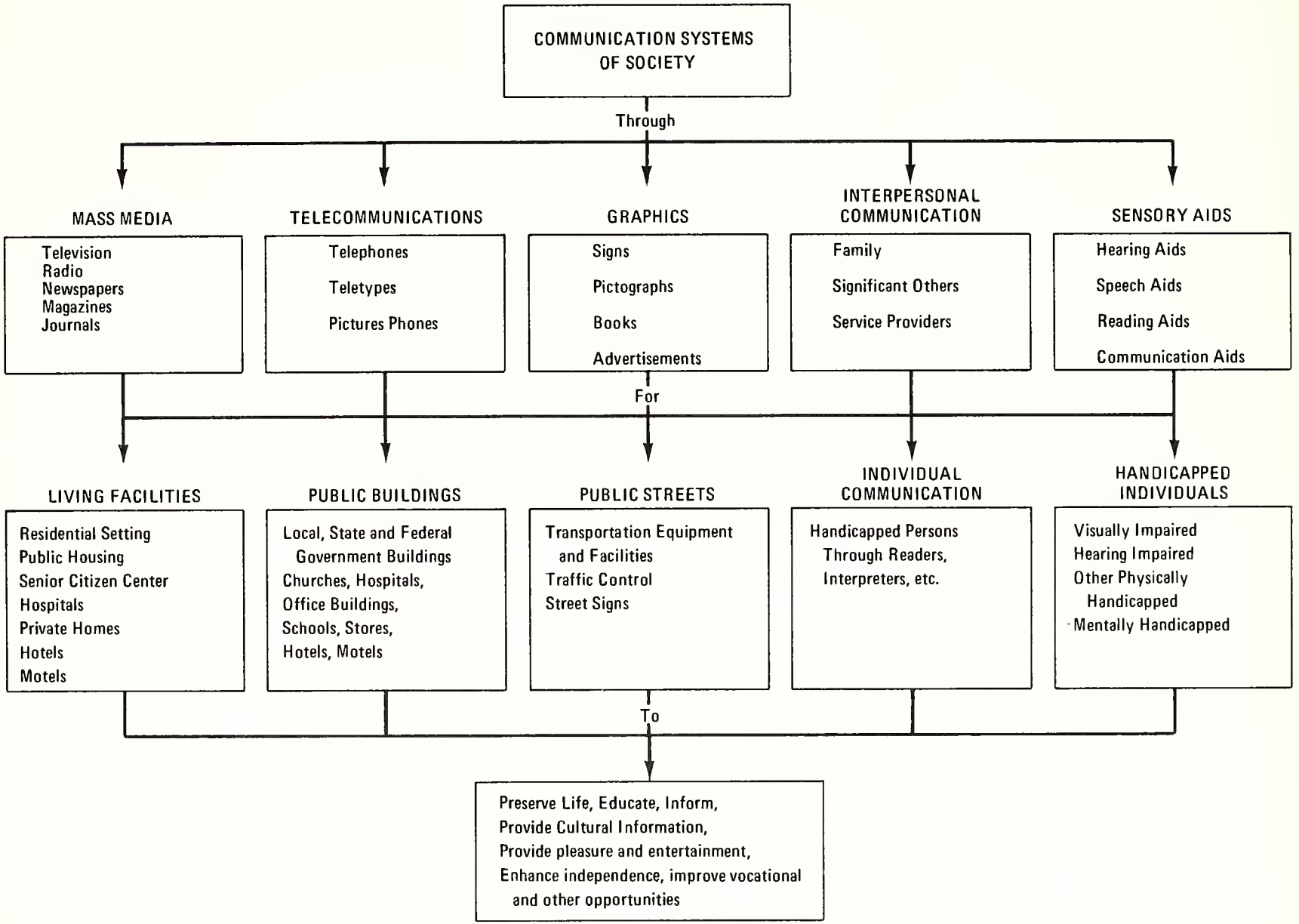

COMMUNICATION SYSTEMS OF SOCIETY
Through
MASS MEDIA
Television
Radio
Newspapers
Magazines
Journals
TELECOMMUNICATIONS
Telephones
Teletypes
Pictures Phones
GRAPHICS
Signs
Pictographs
Books
Advertisements
INTERPERSONAL COMMUNICATION
Family
Significant Others
Service Providers
SENSORY AIDS
Hearing Aids
Speech Aids
Reading Aids
Communication Aids
For
LIVING FACILITIES
Residential Setting
Public Housing
Senior Citizen Center
Hospitals
Private Homes
Hotels
Motels
PUBLIC BUILDINGS
Local, State and Federal Government Buildings
Churches, Hospitals, Office Buildings, Schools, Stores, Hotels, Motels
PUBLIC STREETS
Transportation Equipment and Facilities
Traffic Control
Street Signs
INDIVIDUAL COMMUNICATION
Handicapped Persons Through Readers, Interpreters, etc.
HANDICAPPED INDIVIDUALS
Visually Impaired
Hearing Impaired
Other Physically Handicapped
Mentally Handicapped
To
Preserve Life, Educate, Inform,
Provide Cultural Information,
Provide pleasure and entertainment,
Enhance independence, improve vocational and other opportunities

Figure 1

filed in 1975, the FCC proposed the following ruling:

A. All emergency information must be transmitted aurally and visually; and

B. All emergency transmissions must be concluded with the request, "If you have hearing impaired or blind friends or neighbors, please pass this information on to them."

The second proposed ruling is related to the addition of captions through a specialized decoding device attached to the individual's TV set. This proposed ruling submitted to the FCC by the Public Broadcasting Service requests that "line 21 of the vertical blanking interval of the television broadcast signal be reserved for program captioning information for the deaf." This system would permit hearing impaired persons with the decoding device to receive captions without disturbance to the general viewing public. It is estimated that a station could produce captions for their programs at an initial investment of $25,000 to $50,000 and at a reasonable operating cost. The decoder device, if mass produced commercially, could be produced for as low as $30.00 to $50.00.

It is critically important that these proposed rulings be implemented and that economic barriers be reduced as quickly as possible. Television, properly utilized, could assist in reducing the severe language and academic deficit of many hearing impaired individuals.

For blind persons, a commercially available "television" set has been developed which has both the audio for television channels and radio stations, with Braille dials for ease of use. Since the video receiver has been removed, the set can be sold below the cost of a comparable television set.

Radio

Radio is also a form of mass media which can be used effectively to benefit handicapped people. Although such uses and adaptations have just begun, first attempts suggest exciting possibilities for the future. For example, the Washington Ear, Inc. is a closed circuit radio service for blind and other physically handicapped persons, nursing home residents and elderly home-bound individuals.

This service, located in the Washington, D.C.-Arlington, Virginia area, broadcasts items such as portions of the daily newspaper; information regarding hobbies, sports and shopping; materials of special interest for Black and Spanish speaking disabled individuals; etc. In this way, physically handicapped individuals receive local, state and national information at the same time as their non-handicapped peers receive it in written form.

The equipment includes a special receiver which is loaned free of charge to those who are eligible. The material is broadcast by trained professionals, including some who are handicapped persons. More radio stations throughout the country need to become involved in similar programs in order that all citizens can have equal access to information.

Films and Specialized Materials

Films are consistently used by the American public for both educational and recreational purposes. Frequently, handicapped individuals cannot profit from these films due to inappropriateness of the presentation format or, as in the case of hearing impaired persons, an inability to receive the information from the audio track of the film. Several years ago in an attempt to meet these needs, the Bureau of Education of the Handicapped (HEW) established a special office which originally was designed to provide educational and entertainment films for deaf individuals. However, today the office is known as "Media Services for the Handicapped" and serves all types of handicapping conditions. This office works through a group of special centers which are located throughout the country and are designated to serve specific handicaps. These centers identify commercially produced materials appropriate for the handicapping condition, develop models of needed educational materials, and distribute information to sources in need of the service. In addition, captioned educational and entertainment films for handicapped children and adults are distributed from a strategically located film library on a loan, no-cost basis. One of the major goals of this service is to bring to handicapped people enriched cultural and educational experiences.

There is a variety of needs and problems associated with the production of specialized materials and films. Currently, assessments indicate needs for materials for all types of handicapping conditions in the areas of career education, sex education and drug education. Some of the special problems of production are related to ways in which the information is provided. For

example, mentally retarded children or children with severe language deficits need attention given to developing ways to simplify the language on the audio track. In preparing captioned films, research is needed also to investigate the most effective way for accurately telescoping the language of the sound track into a caption.

Newspapers, Magazines and Journals

Not enough has been accomplished in making the information in our newspapers, magazines and journals available to handicapped persons with special needs. Over 40 periodicals in the nation are transferred into Braille and, as was previously stated, the radio has been used as a means of giving the news auditorially to blind persons. But for those persons whose reading level precludes the understanding of the material in its original form, little is done to adapt the information to make it available in a modified and, therefore, usable form.

TELECOMMUNICATION SYSTEMS

Telephones

In our society today, the telephone is probably one of the most vital communication tools available. Business, pleasure, and emergency situations are all conducted on a daily basis through this system. However, not all segments of the population have equal access to the telephone because of varying handicapping conditions. Reasons for this unequal access can be summarized as follows:

A. Inaccessibility due to the height at which most public phones are placed. Individuals in wheelchairs or those very short in stature cannot reach the phones.
B. Economic discrimination which impacts on the blind individual's use of the telephone. Because long distance calls are more expensive when the operator is involved and because many communities charge for the services of Directory Assistance, the blind person finds himself paying a higher cost for the use of the telephone than does his non-handicapped peer.
C. Inaccessibility for severely physically handicapped people because of the inability to reach the operator via dial or push buttons. (Public and private phones can be equipped with devices that do not require dialing or pushing buttons, but can be controlled by breath.)
D. Inaccessibility to the phone because it is an aural system which cannot be used effectively by many hearing impaired individuals.

Although in many areas of the country there are additional charges for the handicapped person, in a recent issue of Telebrief,* published by American Telephone and Telegraph Company, it stated that handicapped persons should contact their telephone company service representative to seek details on how to obtain a dial rate for operator assisted calls. (The same article also presented a newly developed telephone for severely physically handicapped persons which activates an automatic dialer by a breath-operated switch and utilizes a hands-free speakerphone.)

A problem that has arisen in regard to telephone usage by the hard of hearing population is that of compatibility of the telephone handset with teletypewriters (TTYs) and the telephone switch of hearing aids. Within the past few years most of the telephone manufacturers have produced a more efficient and economical handset which is not compatible with hearing aids and TTYs. This problem has been brought to the attention of the telephone companies who have, in some instances, resolved it.

It is apparent that current technology can provide telephone systems usable by all sectors of society. The desired goal is to convert this knowledge into equipment that can be utilized in all public buildings and can be available in private homes on a low cost basis.

Teletype Systems

In 1964, Robert Weitbrecht, a deaf physicist, developed a telephone coupler which permitted the teletypewriter (TTY) to be used as a communication system for deaf people and those who have lost their speech through illness or accident. When the TTY is connected to this acoustic coupler it sends coded electrical impulses, which are converted by the coupler to a series of tone bursts of specific frequency over the telephone lines. This permits two individuals

*This awareness paper was prepared in April 1976.

with TTY systems to communicate by typing a message to each other.

In the fall of 1975, a survey revealed 5,050 TTYs currently in operation. The current International Teletype Directory listed the following places in the U.S. as having TTYs available: 51 telephone answering services; 15 police departments; 44 churches; 47 community service organizations; 69 schools and colleges; 22 vocational rehabilitation units; a few emergency, news and weather services; some private residences; and Sears and Wanamakers stores in Philadelphia.

There are a variety of types of teletype equipment, ranging from large units for home or office to small portable units that can be used when away from home. The MCM is one such portable system. In this system the letters are presented electronically on a small screen. The Magsat is similar in that it also presents letters on a screen, while the standard TTY supplies the individual with a typed copy which he can retain. Costs for the various TTY systems range from approximately $250.00 to $750.00.

Currently, some progress is being made in providing the teletype systems in a variety of settings. For example, in June 1975, a bill was introduced in the Maryland House of Representatives which, if enacted, would have provided teletype machines in central locations in agencies of State and local government and in other public facilities equipped with these machines (within a toll free telephone district). It was further provided that teletype machines be installed, without cost, in the homes of deaf persons whose gross income is less than $5,000 a year. These machines would be connected electronically to provide a means of communication between deaf persons and the offices of major State agencies. This bill was passed by the Maryland House only, and will have to be reintroduced in the next session of the legislature.

Legislation which pertains to architectural barriers is often cited as a vehicle by which accessibility to communication systems can be attained. The current accessibility standard, ANSI A117.1 (American National Standards Institute) states: "This standard is intended to make all buildings and facilities used by the public accessible to, and functional for, the physically handicapped, to, through, and within their doors, without loss of function, space, or facility where the general public is concerned." This standard was interpreted to apply to all buildings used by the public except for private housing and has been interpreted to imply that to be functional the communication systems must also be accessible. Currently, new standards are being formulated which specifically address the problem of telephone usage within a public building. Issues related to the height of a telephone, the compatability of the phone with currently sold hearing aids, and the use of volume control devices are being considered as the accessibility standard is updated. However, the problems of phone usage for deaf or severely physically handicapped persons have not been dealt with.

Problems relating to the costs involved are serious and must be addressed. For example, individuals using the TTY service for long distance calls will pay at least double the rate for their call due to the length of time it takes to type rather than speak the message. The cost of installing a TTY in a home is at least $250.00. Many deaf people who could afford the monthly cost of a phone bill cannot pay the initial TTY cost—a cost not incurred by the non-handicapped population. No way has yet been derived for use of the portable TTY for phone booth long distance calls since charges are given by the operator who does not have access to a TTY and, therefore, cannot communicate costs to the deaf person on the other end of the line.

COMMUNICATION SYSTEMS IN PUBLIC GATHERING PLACES

Public Buildings

The communication problems (other than those just discussed) which exist in public buildings are basically two-fold in nature. The first problem is related to directional signs in public buildings, while the second relates to the warning system utilized and its ability to notify all persons in the building of impending danger.

Many handicapped individuals experience problems in attempting to use the signage system currently utilized in many public buildings. Non-English speaking persons; blind, deaf and other physically handicapped people; mentally retarded individuals; and those persons suffering from severe reading deficits, often experience difficulties in reading the signs. For example, individuals with physically handicapping conditions which necessitate the use of a

wheelchair frequently cannot see signs because of their placement. Individuals with blindness or deafness cannot receive the information when it is given either exclusively by the auditory or visual channel. In addition, a blind person cannot determine the floor at which the elevator has stopped or be alerted to possible dangers in the building structure. A deaf person cannot be paged in a public building or cannot participate in a tour which is spoken by a tour guide or given by audio cassette.

The problem of emergency warning systems as they relate to physical safety is critical. Most current warning systems are auditory in nature and do not serve the hearing impaired person. Many schools for the deaf do not provide visual alarms and, therefore, jeopardize the lives of their pupils on a daily basis. TTYs are not required in public buildings, leaving the deaf person with no way in which he could report an emergency to the appropriate agency.

Individuals who have mobility problems should also have information concerning accessible escape procedures in public buildings and facilities. This information should be printed in a manner readily understood by *all* handicapped persons.

The lack of appropriate warning communication systems is one of the most critical needs in the United States today. It is a serious condemnation of this society that its priorities have permitted large numbers of its citizens to jeopardize their lives daily.

The Department of Housing and Urban Development is addressing some of these problems, through the award of a grant to update the accessibility standard written by the American National Standards Institute. The Standard relates to the accessibility and usability of public buildings for handicapped individuals. Problems related to the location of signs, the provision of information for blind persons at the elevator area, and indicating to blind persons danger areas by utilizing a rough textured surface, are all being considered by the revisers of the standard. They are also discussing the possibility of placing some seats with volume controls in public auditoriums for use by persons who are hard of hearing; vibratory alarms in pillows at hotels, motels, etc.; flashing signals and auditory alarms in corridors of public buildings and in offices which employ handicapped individuals.

Although the problems of telephone usage and communication systems in public buildings are also being addressed, more attention is needed. New standards will suggest that phones should be no higher than 54 inches. However, it was decided that volume controls on phones in public places were not helpful to hard of hearing persons, and these devices were, therefore, eliminated from consideration. Also, no specific emphasis was given to the communication needs of severely physically handicapped, blind or deaf persons. Since the availability and accessibility to communication in public buildings continues to be a problem, it is apparent that new legislation and/or enforcement of existing legislation needs to be considered.

Public Transportation

Communication is an integral part of transportation. Time schedules, street signs, bus and train stops, paging systems, and announcements of changes of schedules can provide problems for the handicapped person.

The independent mobility of a blind person is greatly reduced when he cannot identify various stops made by local transportation vehicles or when he is unable to identify streets or the various buildings he is passing while on foot. He cannot read signs announcing bus stops and information about routes and bus numbers. However, technological knowledge, if properly utilized, would enable the transmission of this information, commonly received through the visual channel, to be received auditorially.

Many of the signs and messages used in conjunction with public transportation systems are excessively complex, utilizing small print quite difficult to see. Such signs and schedules should utilize large print and clearly contrasting colors and should be simplified for the benefit of those who experience language deficits and reading problems.

Traffic control is another area of concern, particularly for the blind individual. In a few towns in the United States the change of the traffic light is accompanied by a ringing bell with a different ring for each color. In this way the blind person knows when the light is changing and what color it is.

Information provided exclusively in the auditory channel such as paging systems, public address systems in stations and terminals, and on the vehicle itself should also be given in visual form. Many deaf people have described incidents in which the plane they were riding landed in an

airport different from the one scheduled for the landing. The other passengers had been alerted to the change of plans through the public address system. The deaf person leaves the plane thinking he has landed at his point of destination only to find he is in a strange city, for unknown reasons. Since communication is his major problem, he will find it exceptionally difficult to find out why he is in the wrong city and to obtain the information necessary to make appropriate adaptations to his problems. Since there is no telephone communication system he can use, his family and friends will remain uninformed about his whereabouts and if they, too, are deaf, they will be unable to contact their airport to find out what happened to the flight.

This society has an obligation to its members to prevent its citizens from an existence based on fear, which cannot be eliminated, because of inadequate communication systems.

GRAPHICS

The preparation of appropriate graphics is important to the development of a quality communication system. This relates to the production of signs for public buildings, streets, highways, transportation centers, and other public gathering places.

Pictographs

In many European countries the sign system is largely based on pictorial symbols. These can be found in streets, highways, public buildings, transportation centers and are used to symbolize concepts such as danger, curve, railroad crossing, exit, entrance, restrooms, telephone stations, etc. These symbols are used because they communicate effectively to the vast majority of the population, and do not exclude those who, for a variety of reasons, cannot read the language of the region in which they reside.

Although over the past few years there has been an increase in the use of pictorial signs in the United States, the custom is far from universal. Many factors must be considered before a symbol is adapted for public use. Therefore, a well developed and coordinated plan is needed which would address the following needs on a nationwide basis:

A. Selection of those signs which can be symbolized pictorially;
B. Selection of the most meaningful symbol, taking into account the universality of the symbol;
C. Development of a plan for converting present word signs to symbol signs; and
D. Development of a nationwide communication program to educate the public concerning the use of the pictorial signs.

In developing any sign for public use it is important to consider the factors of size, location, color and lettering. The size must be large enough to be clearly visible and the location such that it is easily seen by all, regardless of the level from which the sign is viewed, in sufficient time for the individual to respond appropriately. Color of foreground and background must be sharply contrasting and lettering must be large and clear enough for easy readability.

Color coding in city public transportation systems might be a more effective means of coding transportation routes which currently use numerical, word or letter symbol systems. A color coded system is easily observed and would communicate to larger numbers of our society.

Books, Advertisements and Other Printed Materials

The first issue is the need to include portrayals of handicapped persons in printed materials. This will help to foster acceptance of disabled individuals and develop a better understanding of their abilities and problems. The second issue relating to printed materials is the need for development of literature designed specifically for some handicapped persons.

Although educational publishers and commercial advertisers have made a concerted effort to include ethnic minorities in their publications, little has been accomplished to include handicapped persons in publications. For example, children's readers rarely depict a child with a hearing aid or a child using a wheelchair as part of a group scene in places of public gathering, nor do commercial ads usually incorporate handicapped persons in their format.

Equally important is the development of printed materials produced according to the special needs and related to the problems of the handicapped person (i.e., large type or Braille for the visually impaired, simplified vocabulary and language structure for those with severe language deficits, auditory tape cassettes for

those with visual problems or reading disabilities, and pictorial materials for those who do not develop verbal language skills). Appropriate materials need to be produced which deal with the special needs of handicapped persons. For example, each city should have available, perhaps through its Chamber of Commerce, raised line maps for use by the blind members of the community. Such materials are needed to assist the individual in coping with his environment. In order that commercial firms' need for profit will not preclude the development of these materials, ways must be sought to eliminate current economic barriers to the production of such materials.

The accessibility of appropriate printed materials is also an issue of concern. Many books are not available in Braille and the blind person's breadth of reading is limited accordingly. The library system in England provides a service which attempts to alleviate this problem. A person who is blind can call the library for the reading of any book he desires. Utilizing the telephone connection, a recording of the book requested will then be played for the blind individual, giving him access to many printed materials. The system provides the blind person with the flexibility to stop or start listening, from day to day, at anypoint he desires. Although some good services have been initiated in the U.S., more needs to be done to insure equal accessibility to the printed word for all handicapped persons.

INTERPERSONAL COMMUNICATION

Many individuals within our society suffer from communication problems so severe that it precludes their interaction with a variety of persons within their community. They cannot interact effectively with parents, teachers, community workers, or representatives of public agencies. Nor can they protect themselves by having adequate communication with legal, educational, medical and other professionals.

The Family

The lack of communication within the family structure is the most serious of all deprivations that some handicapped individuals face. Without interaction with parents, ego development, social and educational development, and cognitive growth will be seriously limited. A lack of communication frequently occurs because the parents have received inadequate education at the time of diagnosis concerning the impact of the handicap upon their child. Parents need early counseling and education to assist them in learning to accept their feelings and in acquiring techniques for helping their children cope with the effects of the handicap. This includes the development of skill in communication with their child that is consistent with the child's capacity. It is, therefore, imperative that educational and other agencies assume this responsibility for providing information and training.

Individuals in adult life may lose their capacity for communication. This can result from a stroke, a laryngectomy, hearing loss, blindness, etc. When such trauma occurs, the family is an important focal point of strength for the individual experiencing the problem. The family, however, is also affected by this trauma and often has no means for coping. Services, therefore, need to be provided for disabled persons and their families. These services should include counseling, education and the development of alternative communication skills.

Service Providers

It is equally important that providers of services to handicapped persons have highly developed skills of communication. When a disabled individual is unable to understand the communication system being utilized, many situations arise which create a hazard to good physical and mental health. A doctor or nurse communicating instructions about medication or discussing the treatment for a specific illness is but one example of the critical communication problems faced routinely by many handicapped individuals. Psychological, educational, medical and other treatment cannot occur in an effective manner if communication is not clearly established between the participating parties.

Many children's lives have been seriously affected by misdiagnosis because, during individual testing, the evaluator could not communicate adequately with the child. Children with severe emotional disturbance, which has resulted in communication deficits, are often misplaced and frequently receive inappropriate treatment because the staff is unskilled in nonverbal forms of communication. Many mentally retarded and severely physically handicapped persons must rely on communication systems other than

verbal speech. It is, therefore, necessary that those individuals providing treatment be skilled in the specific communication system of the handicapped person or that interpreters be retained for that purpose. It is only in this manner that handicapped individuals can be assured of their rights to appropriate treatment.

A lack of interpersonal communication results in frustrations which frequently lead to severe emotional problems. Many individuals with deafness, severe multi-handicapping conditions precluding the acquisition of verbal language, and non-English speaking disabled people suffer from this inability to communicate with individual members of society. In order that the rights and privileges of citizenship can be protected, the use of interpreters for deaf individuals and readers for blind persons has been introduced as a partial solution to the problem.

Readers for Blind Persons

One of the ways in which the blind person can reduce the impact of the inaccessibility of the printed word is through the use of readers. Current legislation is pending which would require Federal government agencies to provide readers for blind persons and interpreters for deaf individuals who are Federal government employees.

There is, however, a lack of well-trained readers and no organized channel through which these individuals can render their services. Therefore, the blind person must rely on the few volunteers who currently exist. It has been suggested that a national registry of readers similar to that of the Registry of Interpreters for the Deaf might be an effective means of increasing availabilility and providing qualified, well-trained readers.

The economic question regarding payment exists in most instances where readers are required. Specific action is needed to guarantee the rights of individuals to necessary reading services.

Interpreters for Deaf Persons

Most individuals who suffer from early childhood deafness find many forms of communication quite difficult. The degree to which these individuals acquire skills in understanding lipreading, in utilizing speech, in understanding and utilizing sign language and fingerspelling varies greatly from person to person. Therefore, to guarantee that the rights of these individuals are protected, highly skilled interpreters are needed who can communicate with the deaf person, in whatever mode he finds most effective.

Legal Interpreters

Aspects of current legislation have addressed the use of interpreters in interactions with the police and in the courts.

The Sixth Amendment of the United States Constitution guarantees the right of Federal criminal defendants to a confrontation of witnesses against them and competent counsel. The Fourteenth Amendment secures these rights at the State level. These rights apply to deaf individuals in at least two situations:

A. The deaf defendant as he participates in settings where all other participants can hear.
B. A hearing defendant participating in proceedings where one or more witnesses are deaf.

For example, in the first situation, a deaf person may feel that his presence in the courtroom is meaningless. He has no way of understanding the proceedings of the trial in which he is a participant. The case of *United States ex. rel. Negron v. New York* (434 F. 2d 386, 388) (2d Cir. 1970)) in which the defendant knew only Spanish but the entire court proceedings were in English, has been used to point up the need of the deaf person for a courtroom interpreter if he is to obtain a fair trial.

The Sixth and Fourteenth Amendments grant a criminal defendant the right to confront the witnesses testifying against him. If a defendant cannot understand a witness, he is unable to indicate discrepancies or in any way counteract the testimony. The Sixth Amendment also guarantees the right to counsel in any case where the crime is punishable by imprisonment. The right to counsel can be interpreted to mean the right to an attorney who understands all aspects of the case well enough to build a defense. Without communication there is no way in which a client can share the events of the case with his attorney, thereby violating the essence of the amendment's protection.

In reviewing the current status of State statutes, it can be observed that thirty States

have enacted special statutes providing an interpreter for deaf persons in court situations. Four States also require that the deaf person have interpreting services when he is in initial police custody. Eight states have statutes requiring that deaf persons involved in administrative proceedings also have interpretive services.

SENSORY AIDS FOR HANDICAPPED PERSONS

In the United States over 10 million Americans are handicapped by serious impairment or total loss of their primary senses of vision and audition. The results of these impairments often manifest themselves in vocational, social and cultural underachievement and create an unnecessary dependence on the part of the disabled individual. Sensory aids are viewed as one way in which this dependency can be reduced and the quality of life can be improved.

It is estimated that 1.7 million persons have severe visual impairments while 4.7 million Americans have mild to moderate visual impairments. Of the severely visually impaired population, it is estimated that 400,000 have no useful vision, 300,000 have only marginal vision and 950,000 have limited useful vision. (American Foundation for the Blind). The incidence of profound deafness is estimated at 400,000 while the estimate of all levels of hearing loss is placed at 8.5 million. Of these persons, 900,000 have losses sufficiently severe that they cannot hear words without a hearing aid. Approximately 500,000 people have severe visual impairment concommitant with hearing impairment and another 21,000 persons are identified as deaf-blind. (Schein and Delk, 1972)

However, to date, this population has profited very little from the remarkable scientific and technological advances currently being made in other fields. This may be due in part to the small amounts of money allocated by the Federal Government for research related to the development of sensory aids. When these monies are compared to monies expended for other health related areas for research on an *annual* basis, the following facts emerge:

$220.00 spent per cancer patient
$ 76.00 per cardiovascular patient
$ 1.25 per legally blind patient
$ .50 per visually handicapped patient
$ .41 per hearing impaired patient
(National Academy of Science, 1968)

Aids for Visually Impaired Persons

Sensory aids have been developed in an attempt to reduce the effects of the inability to read print and the mobility problem of the visually impaired. Since this paper focuses on communication problems, attention will be focused herein on sensory aids for reading.

Work has been done to make the printed word more accessible to both the blind and partially sighted individual. The work for blind persons has concentrated on the rapid production of Braille, the preparation of talking books (auditory cassettes) and the interpretation of the printed word into codes other than Braille. Aids for partially sighted individuals have been basically concerned with appropriate magnification.

Aids for Partially Sighted Persons

Aids for partially sighted individuals are frequently referred to as low vision aids. Figure 2 indicates the types of aids that are currently available.

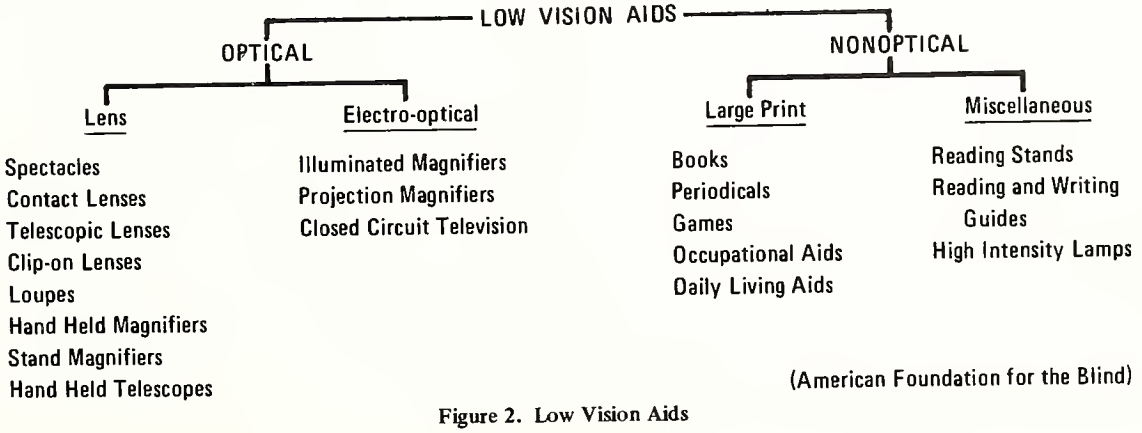


Figure 2. Low Vision Aids

These devices are all based on the principle of magnification and, therefore, attempt to make the print visually accessible to the viewer. As can be observed, they range from the very simple to the highly developed technological systems such as the closed circuit T.V. reading system. Although more needs to be accomplished to improve the aids and reduce the costs, one of the most serious problems today is in dissemination of information to and training of the service providers. The problems of individuals who have visual or hearing impairments are frequently overlooked and the extent of the impact of their problem on daily living is frequently underestimated. Therefore, there are large numbers of partially sighted persons who do not know they can be helped and who have not received the training necessary to utilize aids effectively. The need, then, is for a concerted, systematic effort to provide a more effective service delivery system and to alert the general public to ways in which partially sighted individuals can be assisted.

Aids for Blind Persons

Blind individuals have expressed a need for both Brailled materials and recorded cassettes. In 1962, a study of blind college students by "Recordings for the Blind" indicated that 34% of 402 blind college students preferred auditory cassettes for long, descriptive, non-technical texts and 91% for light reading. Many students wanted Braille texts in areas where they are not available. The students felt that Braille was important in learning formulas or other tasks requiring memory and, therefore, requested Brailled materials in language courses, mathematics and other complex content fields.

Normal speech rate of 180 words per minute is too slow for many blind persons. In the past, speeding up the tape has resulted in a change of voice pitch to higher frequencies. Currently, experimentation is being done with compressed speech, a technique for speeding up the rate while retaining intelligibility, and a few electromechanical speech compressors are now available.

For voice recording and playback, there is a variety of commercially available disc and tape equipment. The Library of Congress has adopted a cassette tape format for its "talking books" program. (The Library of Congress recorder provides a quick-scan reference using the fast forward speed to play back page numbers on the normal voice track.)

The production of Braille books is centralized in the Library of Congress under the Books for the Blind program which subsidizes Braille and recorded books produced by the American Federation of the Blind and the American Printing House for the Blind. In addition, the Library of Congress trains and certifies Braille translators who provide Braille transcription services throughout the country on a voluntary basis. Although much has been done to make Brailled readers available to blind persons, the delivery of services is not as fast and comprehensive as is needed. The lack of Braille books can be illustrated by the fact that in 1964, in the United States, 28,500 new titles were published, but only 600 were Brailled for addition to libraries for blind persons.

Recent technological advancements have concentrated on speeding up the production of Braille. In 1959, a systems approach to computer Braille production was initiated at the Massachusetts Institute of Technology. Work has continued successfully at the American Printing House for the Blind and between 1964 and 1970 it has produced over 1,000 volumes using computer translation. Atlanta, Georgia has been using a computer system for several years and can deliver Braille material to all blind school children in the Atlanta area with a turnaround time of about one day.

The Transicon (an individual computer) is a recent development from Israel. It is operated by the blind person himself. It reads at 22 characters per second at a projected cost of between $1,000.00 and $10,000.00. This compares with current commercial units which read at 1,000 to 100,000 characters per second at costs exceeding $100,000.00.

Other aids have been developed which are commonly referred to as direct reading aids and concentrate on converting the printed page into a code to be interpreted by the blind reader himself. For example, in 1972, the Stereotoner was developed with this need in mind. It scans the printed page and converts the print into musical chords to be interpreted by the reader. The Optacon, also a direct reading aid, scans the page with a small optical pickup manipulated by one hand and sends a tactile copy of the letter to a finger of the other hand.

Much more experimentation and research is needed to provide a direct reading aid which can

be used by the majority of blind persons, at a reasonable cost.

Aids for Hearing Impaired Persons

Aids for hearing impaired individuals have focused on the improvement of hearing and speech and the conversion of the auditory stimuli to a visual or tactile signal. Hearing aids are developed on both an individual and group basis. The induction loop group system is one of the newer successful advancements in this area. Although hearing aids have advanced in quality, cost factors continue to create a problem. For example, individuals in low income brackets utilize only one half as many aids as do persons in higher income brackets. It has been estimated that the approximate cost of the parts for a hearing aid is $24.00; the wholesale price, $140.00; and the average retail price, $350.00. (*Consumer Reports*, May 1971) Commercial producers claim this mark-up is necessary because of the low volume of sales.

New developments in individual hearing aids have basically been concerned with the frequency range of the hearing aid, attempting to extend the range, focus the range, or convert information from one frequency range into another. Thus far, there is no conclusive evidence that any of these techniques has significant value.

Current research is focusing in the area of development of electrocortical aural prostheses (devices to directly stimulate the auditory area of the brain). Although the work is challenging, much more progress needs to be made before significant results can be obtained.

Speech training and speech perception aids have been developed which focus on the transference of the auditory signal into visual or tactile information. These aids are to be used by the hearing impaired person to improve his perception or to monitor his speech. These devices range from simple displays of lights to complex pattern responses to sound. The computer is also being investigated as a possible aid for speech development.

Aids for Deaf-Blind Persons

Aids in this area concentrate on converting visual signals into tactile impressions of one type or another. One of the most useful devices is a typewriter, known as the Tellatouch, on which any person can type a message to the deaf-blind person who receives it at his fingertips in a Braille impression.

Aids for Other Physically Handicapped Persons

There are sensory aids which can assist physically handicapped individuals who have some degree of difficulty in speaking and other persons whose handicapping conditions affect their manipulative abilities. The selection of sensory aids to be used by these individuals depends on the person's language and communication skill, his physical abilities and the functions to be fulfilled by the communication system.

Communication aids for this group of handicapped individuals can be categorized in the following manner:

A. Scanning aids;
B. Encoding aids; and
C. Direct selection aids.

A *scanning aid* is one which presents choices to the user sequentially and the user indicates his selection by signaling when a desired choice is presented. An example of a scanning aid is the Alphabet Message Scanner. This device permits the individual to communicate by selecting letters, numbers, words or phrases on a display panel. The cost of this device is $300.00. The Auto-Com is another fully portable aid which transfers the letter selected by the individual on a communication board to a T.V. screen (approximate cost $2,500.00). Aids have been developed ranging from very simple communication boards that have a variety of communication symbols on them (i.e., pictures, Bliss symbols, printed word, etc.) to highly complex electronic instruments. Over sixty such aids have been produced and are commercially available today.

Encoding is a technique in which the desired output is imprinted by the aid by multiple inputs which must be memorized or looked up on a chart. The Code Operated Selector is an example of an encoding aid. With this device a code is programmed into the unit by two switches which can be operated by hand or foot. The code used is the Morse Code with one switch producing the dot and the other the dash.

A *direct selection aid* is one in which the output desired is directly indicated by the user. In a direct selection aid, there is a key or sensor area for each possible output selection. Anrowd is an example of a direct selection aid. The

system has three control modules, a typewriter, a pneumatic control which controls the display of letters when one sucks or blows on a tube and a control which displays letters and is operated by pushing a combination of two out of eight switches.

In process of development for individuals who are unable to speak (i.e., some persons who are severely physically handicapped, stroke victims, individuals with laryngectomies, etc.) is a device known as the Talking Brooch. This aid has a typewriter keyboard which can be held in the hand and a display brooch which is worn by the individual. The person types out his message which then appears electronically in print on the brooch. This system is not commercially available at this time, but holds much promise for the future.

For those individuals with severe physical handicaps which preclude the use of their hands, a new typewriter, the Possum Typewriter Control System, is available. This device works in a variety of ways and is adaptable to the individual's specific needs. For example, it can be operated by suction from the mouth or by a knee, head, or foot switch.

CONCLUSION

Legislation has been cited as a means of providing better services for handicapped persons. However, new legislation is not always the answer. The anwer frequently lies in the implementation of current legislation. Economic barriers are also present. The low incidence of many handicapping conditions causes commercial firms to question how they will make a profit on any materials or equipment they develop or sell. It is important to help these firms understand that many of the items which they might produce have a market far greater than the specific target population for which they are designed. For example, the purchase of a TTY by a family with a deaf family member will encourage the purchase of additional TTYs by relatives or close associates who hear. This is true except in those cases where the aid is specific to the nature of the handicap (i.e., low vision aids, hearing aids, etc.). In these cases new ways must be sought to reduce the cost and make any aid which reduces communication barriers available to all persons, on a low cost basis.

Communication is basic to man. Without the ability to communicate ideas, needs and feelings, the individual is reduced to a passive observer of life. His level of independence is affected. Therefore, to deny communication is to deny basic human rights.

BIBLIOGRAPHY

A Statement of Shared Needs and Goals. Final Report of the Illinois Conference of Handicapped Citizens, 1975.

George, B.J., Jr. *Legal Status of Interpreting for the Deaf:* Report, Center for Law and the Deaf, Washington, D.C. 1975.

Goldfish, Louis H. *American Foundation for the Blind Report on Vision Impairment Statistics*, 1972.

"Hearing Aids: What the Buyer Should Know." *Consumer Reports*, May 1971.

Human Communication and Its Disorders: An Overview. U.S. Department of Health, Education and Welfare. Public Health Service. National Institute of Health, Bethesda, Maryland 1970.

Improving Services to Handicapped Children. Health, Education and Welfare Report. 1974.

Kinney, Richard. *Touch Communication.* Hadley School for the Blind, Winnetka, Ill. 1969.

Malone, Joy, *Deaf People and Telephone Communication with Government: TTY Means and Ways.* Graduate paper, unpublished, 1976.

Mann, Robert W. *Technology and Human Rehabilitation: Prostheses for Sensory Rehabilitation and/or Sensory Substitution.*

National Center for the Law and the Deaf Newsletter. January, 1976.

National Workshop on Non-Vocal Communication Techniques and Aids, Proceedings. University of Wisconsin, 1975.

News-Federal Communication Commission Report No. 11457. December, 1975.

Schein and Delk. *The Deaf Population of the United States: A Census Report.* NAD, Silver Spring, Maryland, 1972.

"Selected Research Development and Organizational Needs to Aid the Hearing Impaired." National Academy of Engineering, 1973.

"Sensory Training Aids for the Hearing Impared," National Academy of Engineering Proceedings, 1971.

Smolski, Walter. *Telephone Typewriter Communication for the Deaf*, A.S.H.A., March 1976.

State Wide Bulletin—Illinois Association of the Deaf, Winter—1976.

EMPLOYMENT

Awareness Paper Prepared By

Richard T. Sale
White House Conference on
Handicapped Individuals

TABLE OF CONTENTS

	Page
Overview	207
Interests and Attitudes	207
Attitudes of Employers	207
Attitudes of Disabled People	208
The Law	209
Resolving the Differences	210
Education and the Handicapped	211
Career Education	211
Training	212
Placement Systems	212
Rehabilitation and Industry	213
The Handicapped and Job Success	215
Conclusion	216

AN OVERVIEW

The problems of unemployment and underemployment among the nation's population of physically and mentally handicapped persons are serious. They persist despite remarkable improvements in medical care, rehabilitation, right-to-work legislation, modification of environmental barriers, placement programs and gradual changes in attitudes among disabled individuals, employers and the general public.

There are more than 35 million physically and mentally handicapped persons in the United States according to the 1970 Census. Of that number, approximately 11.7 million are listed by the Census as having been disabled for more than six months, not institutionalized and between the ages of 16 and 64.

At the time of the 1970 Census, over 6 million disabled persons were not in the labor force. Some were not working by choice. They pursued roles as students or homemakers, or participated in programs that would cause a loss of subsistence funding if the individual accepted paid employment. But many of the handicapped persons are prevented from joining the labor force as a direct result of environmental and attitudinal barriers imposed by our society.

Clearly, the state of unemployment and underemployment among disabled men and women can, and must, improve. The cost in loss of valuable human resources, forced dependency and consumer purchasing power is far too great to be reinforced from a point of logic or policy determination.

INTERESTS AND ATTITUDES

One cannot discuss attitudes related to employment and disabled persons without first discussing interests, for the two are entwined in an intimate way.

Society is full of groups whose chief aim is their own success and perpetuation. We are not criticizing or endorsing such a thing; we are merely describing it. No man sees his interests as another sees them. As figure A sees his desire to make money as ambition, his neighbor, B, may view it simply as greed. Or where, by some new law, B gains a right to which he feels justly entitled, A (who already enjoys the right) may see B as merely trying to take what is not his. All social, economic and political questions are essentially the struggle of one interest with another for a larger share in the sum of society's benefits. Or, to phrase it colloquially, as a famous writer has done, you have the Ins and the Outs: the prosperous and established, and the wanting and ambitious. The Outs want to have what the Ins have and to get where the Ins are. Since the field of prestige and privilege in any society is not very large, the belief of the Ins is that the more who enter it, the less will be the share for each. So, the Ins want to keep the Outs out.

Now, how is an interest related to an attitude? In what relation do they stand? An intimate one, since one's attitudes are often a product of one's interests. There can be no doubt that an attitude is a social product, and often a product of the social position, or class, that one finds oneself to be in. A person's position in life, the amount of money he earns, the kind of culture he can afford and the status he enjoys, all act to influence the kind of opinions he will tend to have. This is so in almost all cases. One's attitudes usually act, in part, to defend the importance of what one is, has or does; in brief, one's interests. To describe conflicts in this way does, it is true, leave out a great deal. On the other hand, it has the advantage of not making a moral melodrama out of differences of outlook. It implies that any group of interests is made up of groups of people who share that interest, and that no group of people is any better than any other nor any worse. The only thing that differs between them, after the view they take of themselves, is their relative social positions and economic power.

ATTITUDES OF EMPLOYERS

Employers are one of the most prestigious, largest and most important social groups in our society. The undeniable importance of their function has endowed a great many employers with a belief that their moral standards are superior as well. Even the amount of their economic rewards is assessed on the basis of their better character, for businessmen believe that if you are the author of great accomplishments, you have a right to expect great rewards. The business community basically believes it should be paid out in accordance with the importance of what it puts in. Such a system of thought is a basic part of America's way of

thinking, and it has provided to all of its people an unprecedented incentive, for it encourages all those who feel they have merit to exert themselves in the cause of their own success.

To put it another way, men are going to be morally proud when their pride is based on real and substantial achievements. Businessmen are correct when they acknowledge that their economic position is one of great power. The whole social structure rests upon the kind of labor that they do. The abuse to which employers are subjected—the rhetoric that would condemn them as monsters of bias, who put profits before principle and greed before their fellows—is the kind of abuse that always nips at the heels of success. It is a tribute to the preeminence industry enjoys. Businessmen are, in fact, just ordinary human beings, not better nor worse than any other group of people who have the success of their own personal interests at heart. Employers are not insensitive. Rather, they are people who want to get on with what they regard as their own aims and who do not like to be told what to do.

In just the same way that handicapped people are convinced they know their own needs best and become uncomfortable when the non-handicapped attempt to speak for them or pretend to know what those needs are, so are employers impatient of being dictated to in matters they regard as knowing best themselves. Hiring workers of any kind is, for an employer, a business practice, not an act of social conscience, or a display of tenderheartedness.

In the past, appeals made to employers for them to hire handicapped people were made in terms of money—that it was good business to hire the handicapped. This is a thing which handicapped people have come to resent, for they see the hiring of disabled people as an issue of human rights—a recognition by employers of the moral rights of all Americans to work. But in the past, no one—not even the bulk of the disabled themselves, saw it in this way. Seeing it in this way is, we agree, a wonderful progress of conscience, except one must remember that in the past, business, labor and government saw the matter in the only way it could—as an economic, not a moral issue. As far as an employer was concerned, there were workers who could perform the work and those whom he suspected could not. In business, defects of performance, added expense, serious inconvenience—these were sober business factors and had nothing to do with whether or not one had a hard or a soft heart. The grounds that industry had to act from were business grounds; that, plus an unawareness or apathy of the government as the deplorable predicament of handicapped people led everyone to go right on with hiring practices which experience had never led them to question. It has taken the passage of Section 503 of the Rehabilitation Act of 1973 for many employers to become aware at last of what they were doing. "We had a medical department that thought it was saving company money by only hiring Greek gods," the *Wall Street Journal* quoted a personnel officer for a large midwestern manufacturing firm. "We have completely abandoned that approach. Now we're trying to fit a person to a particular job."

ATTITUDES OF DISABLED PEOPLE

It is hardly a surprise that as years passed and as other portions of the populace—other minorities—succeeded in obtaining rights denied them, the impatience of handicapped people began to mount. Anxieties, mortifications, slights and deplorable embarrassments of every description are not economic factors. Yet they were (and for many still are) the essential stuff of the handicapped person's everyday life. The enormous number of public annoyances in this country reminded the disabled persons of their hardships and acted to double them.

As a group, most disabled people balked at the moral pretensions of industry, labor and public employers. They shared the judgment of sociologist C. Wright Mills that, "People with advantages are loathe to believe that they are people with advantages. The disabled saw those influencing employment not as a group of individuals whose character was made of better, superior stuff, but a group who had a greater share than other people of those things and experiences that are most highly valued . . . which include money, power, and prestige and all the ways of life to which these lead."

It was all very well for employers to want to push forward their own interests, but when the disabled person compared his lot with that of employers, he found it to be singularly grim. Where an employer or member of a closed shop was well-to-do, disabled families of four were finding it difficult to earn more than $7,000 a year.

Industry's view of itself was made especially irritating by the fact the disabled knew themselves to live in a country whose central political rhetoric talked incessantly of equality of chance, or a system of society that was open to all, free to all, full of hope for all. And even while the disabled saw it was true for a large portion of the country's people, they saw when they looked at themselves that their own lives were in dramatic contradiction to the dream.

Even then, it was only slowly that handicapped people began to be aware of the problem the attitudes America's employers posed to them. When it came to obtaining work, the question was, what was the greatest problem a handicapped person had to face—his own handicap or those attitudes? Since employer studies, like the DuPont study of its disabled employees, had proven that handicapped people had an ability on the job equal to the nonhandicapped in accomplishing work of the same kind, why was it so hard to find work?

The situation was intolerable and the disabled, at last aware of themselves as the Outs, asked for things to be made equal between the two parties. To effect this, they appealed to the public and the courts.

THE LAW

For years the stock response to employers was that they did not discriminate against anybody on the basis of a handicap, and that they had no objection to hiring handicapped people, provided that disabled job applicants were qualified to do the work. That this view was less than complete was made clear by the passage of the Rehabilitation Act of 1973. Section 503 of the Act makes it illegal for all companies who do at least $2,500 worth of annual business with the government to discriminate against handicapped individuals in employment practices. It also requires them to design "affirmative action" plans for hiring handicapped people or face loss of Federal contracts. More than 2,000,000 companies and institutions that employ more than one-third of the U.S. work force are affected.

The passage of the Rehabilitation Act ended any argument that industry had been making of its innocence of discrimination against handicapped people in its hiring. No law prohibits what does not exist. By attempting to correct a wrong kind of behavior, a law acknowledges that such behavior does indeed take place. Thus, complaints by handicapped people over the years appear at this point to be indisputably true. According to the *Wall Street Journal*, disabled persons have so far filed job discrimination complaints against such companies as General Motors Corporation, Western Electric, RCA Corporation, U.S. Steel and many other industrial giants, a total of 423 complaints as of January 1976.

Industry sees itself as having to be on a constant defensive because every new movement of a minority toward its full rights seems to take industry as a target. Business is not opposed to human rights, but the grounds it has to act from are business grounds and reforms are expensive. One must understand that the traditional attitude of industry toward most movements of social reform has been to agree that it wants to see that needs are met and it is willing to help meet them, but *only* if it can be done without economic detriment to itself. Business reasons that it ought not to give away to any cause more than it can spare, it should itself be in a want and should have to seek the economic aid of others and would only, by thoughtless charity, have replaced one social injustice with another. Their own situation requires they study their own interests first. Labor, in other ways, poses similar arguments based on self-interests.

In fairness to employers, there *are* perplexing aspects of the Act. For one thing, Section 503 requires that a 'reasonable accommodation' be made for the disabled worker, which may mean that companies may have to make expensive changes in offices and factories. And firms' outlays for life and health insurance 'seem sure to rise because the law covers persons who have suffered serious illness,' as the *Wall Street Journal* notes. 'Must a company spend thousands of dollars to accommodate an employee's handicap?' asked the U.S. Chamber of Commerce which noted that until the question was settled, there would 'hardly be a large push by companies to employ the handicapped.'

The handicapped retorted to this by asking when—ever—had there been a 'large push' to employ handicapped people in this country? And if there had been, why was there a need for a law? The disabled saw in the Chamber's *kind* of statement new evidence of the same old selfish bias, the same indifference to moral obligation, and suspected that employers were simply casting about for new excuses that would

enable them to go on in the same old way they always had. Those mose militant of the disabled were convinced that they could obtain justice only by filing complaints and fighting the matter out in the courts. Further, the same debate occurs between disabled advocates and organized labor, and governmental institutions and agencies.

RESOLVING THE DIFFERENCES

When difference of opinion occurs, it is best to assume of the people you oppose that they are not entirely unlike yourself. Nothing makes intelligent thought more impossible than to suppose that your opponent is totally wicked while you are in the right.

Employers are made nervous at being an object of suspicion of disabled advocates. Employers sometimes cannot understand the urgency of handicapped demands or they are offended by the tone in which they are made. This happens because employers are secure. They enjoy an ease and dignity which can only arise from the inner certainty that comes when one's place in life is a definitely established fact of one's world, from which one cannot be excluded, ignored or snubbed. That same dignity and assurance are what the handicapped are seeking through jobs to achieve, and yet employers do not yet seem to understand this fact. The question then becomes, how can both sides come to understand each other? How can both sides enter each other's point of view?

Two courses of action seem intelligent at this time: campaigns of public persuasion and use of the courts and the law. And even the second requires use of the first. Let us then speak to campaigns of public information first.

All campaigns whose purpose is to inform the public mind recognize that no one can have sympathy for, or take an interest in, what they do not know anything about. The point is not as simple as it sounds. It is hard to enter the feelings of another. What a man feels about a matter is based upon what he knows (or imagines he knows) about it. Their action is an attempt to put themselves in another's place, not imaginatively, but physically. Some misfortunes are unimaginable, and it would seem the daily lot of handicapped people is beyond the imagination of most of us. The conclusion then would seem to be that we cannot take an interest in what another experiences until we get placed in a situation which forces us to experience the same thing.

Hence, public information campaigns, especially television spots, are important. It is not simply that the medium reaches such an enormous number of people; the importance lies with the nature of the medium itself. Sights, like words, have a meaning. If you see a person in a wheelchair confronted by an office building with a flight of steep steps, one doesn't need to say 'barrier,'—one experiences in part what the word 'barrier' means.

It must be stressed that for the majority of employers, as for the majority of our people, a handicapped person is something they do not know firsthand, but is an imaginary entity which cliche, rumor and stereotype have labeled with some name or other, but whose truth is hardly dependent upon the actual facts. When the popular mind thinks of handicapped people, it thinks of a mere figment which they suppose to be true.

The danger can come when people view an involuntary fault, like ignorance, as a willful fault, like persecution. The understanding of employers of the hardships of disabled people is far from sufficient, as we have said. But this is partly because the needs of handicapped people are special needs. It is an error of logic to claim your needs are special and expect them to be widely known and understood at the same time. Yet some handicapped advocates do this. The same advocates also talk as if employers were totally wicked and yet the appeals these advocates make to them are usually couched in moral terms, using words like 'justice,' 'freedom,' 'dignity' and 'equality.' The fact is, employers are not wicked. They have been acting unjustly, which is not the same thing.

Every group puts its own interests first and only takes pain to be fair to others when it is compelled to. When men learn to act from moral obligation, there will be no need for law. Until then, there is a need for law and a need to understand the need for it. A law is not a tool for quarreling, as some management representatives and public administrators might suppose. It is, in fact, by history and design, a means for reconciling competing and hostile interests—a part of the civilized process by which a society ensures that all of its members shall be treated in the same way. The law is the use of force, but it is force used for the purpose of confirming

agreement, of restoring a balance missing between two unequal parties. A campaign of public information can both help explain the law itself and make clear the desperate needs it helps to meet.

The main thing to remember is that this struggle of disabled individuals is no different than the struggle of any other minority group in our culture to obtain and enjoy its just rights, a just right being that which is due to someone by fair claim. To view the matter in this way stops it from being a melodrama taking place between good and bad.

The handicapped are impatient—what they want in seeking work is due them by just claim. But society is a creaking, cumbrous thing of which it can be said only that it does move and however painful and slow, progress does take place.

EDUCATION AND THE HANDICAPPED

We need at the outset to define what we mean by education. It is the tradition of liberal arts to define education in the sense of development of mental powers or the formation of moral character. We do not mean to use the word in this way. We are talking about education as something which enables a person to earn a living. We are talking about education only in connection with a livelihood, a job that fits in with the needs and requirements of a society. The choice of a livelihood, a job, is limited by the capacities of the individual, and also by the kinds of activity favored or discouraged by the society the person inhabits. People view the idea of a livelihood differently. Some people will view their job as a means of obtaining power or distinction—other will be content to earn a very modest living in order to pursue a vocation which seems more worthwhile to them than it does to their neighbors. Still others want to live in what they accomplish in their leisure time.

Handicapped individuals may hold all of these views, but it is the view of this paper that what handicapped people require is an education suited to their own special needs and that the chief aim of such education should be to enable its student to earn his own living through a job.

We know that one of the single greatest defects of American education is that it educates people for jobs which do not exist. As it stands now, there is no established national system of manpower and curriculum planning, which means that education is always out of step with the job market. The difficulty is serious.

It is the assumption of this paper that it is up to educators tc make certain that no training is undertaken by handicapped clients unless the educators have a clear idea of what the training is for—which means a definitely available job. It is also our recommendation that detailed job market knowledge can best be obtained if educators and businessmen worked together. An interesting example of this kind of fruitful cooperation can be seen in the Work Orientation Program for the Severely Disabled College Student, set up at the Human Resources Center at Albertson, Long Island, in New York. The students taking part were referred to the program by the local Office of Vocational Rehabilitation. They spent their first week as part of a 'team' whose purpose was to help them assess their abilities realistically and to teach them techniques required to look successfully for a job.

In the words of the authors of an article about the program, Houseman and Smith, ". . . a close working relationship was developed between the business community and rehabilitation personnel . . . relevant part-time employment or summer employment was secured for those students who had successfully completed the orientation . . . The participating employers agreed to pay one-half the student's salary ($1.00 per hour) for a maximum of 400 hours. The Project Coordinator provided follow-along services for both employers and students."

The employers were as large as BankAmericard, the American Red Cross or as modest as local museums and hospitals. Throughout the student's four years in the program, the rehabilitation counselor worked with the student and the employer to make sure that the skills the student was being taught were ones which the employer could make full and prompt use of, once the student had completed the course. Jobs included such positions as library aide, social work assistant, draftsman and many others. Out of the 29 students who participated in the program, 21 were placed in jobs after graduation.

CAREER EDUCATION

Career education is considered as an area within the total curriculum which is aimed at

participation in an occupation or other productive endeavor. A successful career education program should emphasize the strengths of the participants and should emphasize labeling and limitations. This is especially important for handicapped persons who have been made painfully aware of their shortcomings. The range of potential among students should also be taken into account in order to gear training to specialized needs.

In addition to training in a specific vocation, students must also receive instruction in personal skills, work habits, etc., in order to equip them for changes in their vocational situations and to maximize their level of independence.

By using the resources of the schools in education, business and industry become involved in the development of curricula and training programs, their reluctance to hire handicapped persons can be substantially diminished. Actual on-the-job experience provided by business and industry can also help to alleviate the fears and insecurities of the handicapped person.

Agencies which have provided some form of career education outside the schools have included local and state vocational rehabilitation programs. The National Advisory Council on Vocational Education, however, recently criticized the vocational rehabilitation program and called for more services to special populations. They also noted that the more severely handicapped were the victims of agency policies which rely on rapid case closures for demonstrations of performance.

TRAINING

Training on all levels continues to be an integral part of a handicapped individual's potential for securing and succeeding on a job.

The Federal Government, recognizing the need for adequate job training, has made major fiscal investments in model programs that serve deaf individuals. Two of the most successful are St. Paul Technical Vocational Institute (TVI) in Minnesota, and the National Technical Institute for the Deaf (NTID) in Rochester, New York.

TVI and NTID are based on the principle of establishing educational and training programs based on the long-range needs of business and industry. Industry participates in establishing both the curriculum taught and the evaluation of programs to keep it current.

While TVI is primarily regional and provides training above the high school level for deaf students, NTID provides technical, professional and masters degree programs in business, engineering, science and health services. NTID is located on the hearing college campus of Rochester Institute of Technology, which has the added feature of deaf and hearing students learning and living together, providing an atmosphere that will compare to what deaf students will face when they graduate. At NTID, personal and social development of a student is as important as the technical skill acquired.

In both TVI and NTID, support services such as interpreting, note-taking and tutoring are provided for students who require them.

In the final analysis, it is the job placement success that sets these programs apart from others. TVI has a 93 percent job placement record, while NTID stands at 96 percent.

PLACEMENT SYSTEMS

A recurring dilemma has been echoed many times by employers and professionals in the field of vocational rehabilitation. Employers contend that workers cannot be found for the available jobs that they feel handicapped people can do. On the other hand, professionals in rehabilitation contend that employers are not receptive in trying handicapped individuals for jobs that are not so-called positions reserved for the handicapped.

Several similar concepts have been introduced to solve this dilemma. Programs such as selective placement, reengineering, job modification and job restructuring have been providing solutions that are beneficial to both employers and workers in the field of vocational rehabilitation.

The U.S. Civil Service Commission has appointed selected placement coordinators in each of its Federal agencies to assist in selective placement of severely disabled people. Many times the job must be modified to take advantage of the special aptitudes and skills of the person. An example of job modification would be for a blind testing specialist to trade off the duties of scoring the test in lieu of administering the test for another specialist. In turn, one of his co-workers perhaps could score all tests and the blind testing specialist could administer his fellow worker's test. This job modification will still allow for the total job to be completed with both individuals having contributed skills for

which they were best qualified. The same concept of job modification can also be accomplished in the private sector by taking a new look at old jobs. However, sometimes a job may not need to be modified, but simply restructured to accommodate a severely handicapped individual. On an assembly line, certain tasks simply may be switched.

The present stage of technology has also made it possible for some jobs to be reengineered. Machines that are operated by hand controls can many times be reengineered for foot controls. Reading machines have been devised for blind individuals and special assistive devices for persons with diseases of the central nervous system. A nonprofit organization in Washington, D.C. has had many successes in selective placement by utilization of reengineering. The main objective of this organization is to compile lists of job-ready clients and circulate such lists to various potential employers and organizations. Once an employer shows an interest in a client on the list, resources are then obtained to best match the person and the position.

The concept of private organizations becoming involved in the job search and placement process of the severely disabled is becoming more common throughout the United States. An organization in the northeastern part of the United States, operating with CETA funds, has developed a model program that has received wide recognition throughout the United States. Potential job seekers first register with a job expeditor. It is the expeditor's responsibility to become familiar with the characteristics and skills of the severely handicapped individual seeking employment. This is accomplished by utilization of the following process: an intake interview, background follow-up, referral to job developers, client follow-up and supportive services.

The primary responsibility in job development is to establish and maintain industrial contracts. Then a job developer will forward resumes to arrange job interviews, analyze work progress, do follow-up on the position and the employee and exit interviews (when necessary). In many instances, the job preparation and placement only partially satisfy the needs of the employee. Many times, outside circumstances can add to the success or failure of the job continuance. Such factors as transportation, health services and special equipment can play an important role in the work environment.

The new emphasis on job placement services and those ancillary areas surrounding them is a positive step forward for the handicapped individuals of America seeking employment. Workers in the field of job placement feel that special emphasis must be devoted to the job search and job placement process to exploit fully the vocational rehabilitation system functioning in America.

REHABILITATION AND INDUSTRY

Rehabilitation is an activity supported by the middle class. The goals of rehabilitation programs, whether made explicit or not, are the ideals of the middle class—a respect for status, money, comfort, ease, security of position and an admiration for job success. A great deal of the modern world holds such ideals in disdain. This paper cannot then be addressed to them; it is addressed to people of the middle class, handicapped and nonhandicapped, to whom work is a value, addressed to people who are respectful of the financial and status rewards that a job can produce. In other words, the assumption made in discussing rehabilitation here is that it will have as its aim a steady and remunerative job for the disabled worker. It is also assumed that the purpose of rehabilitation is not only to get the disabled client a job, but also to help him to remain on it and, when appropriate, to have an opportunity to experience upward mobility in the corporate personnel ladder. In any job, a balance must be reached between what a worker wants from his work and what his work demands from him, and it is obvious that tenure is a most basic indication that a proper balance has been reached.

When we speak of rehabilitation, what we have in mind are really three things—rehabilitation itself—reducing the problems of clients, liquidating their physical or mental disabilities and training and placement. Of the three, we are going to concentrate upon the last. It is well known that placement systems in this country are far from being satisfactory. Let us take the results of the Greenleigh study on workshops, for example. Workshops in this country serve 410,000 clients a year. Yet placements by workshops amount to only 10 percent of all clients from the 2,766 workshops that make up the entire workshop community. While clients of workshops praise and praise highly the

rehabilitation that workshops offer, they are keenly aware of how poor the system of placement is. Other, more general studies present equally dismaying results. The discrepancy between job training and job placement was determined by Reed and Miller in a study that found that 45 percent of all clients had been inappropriately placed. That was in 1971.

Critics try to account for placement failures in a variety of ways. Some attack the rehabilitation counselor, claiming his education is inadequate, his attitude toward handicapped people is defeatist, his contact with community employers far too limited to be of any good. Some attack the U.S. Employment Service and State Employment Services for being ineffectual, noting that the recession has sharply cut back their staff and placement services. It is not our purpose here to try and anchor the shortcomings and defects of the placement system to any group of people or to a particular institution. We begin from the point of admitting that the placement system, for whatever reason, does not seem to work very well, and perhaps it would work better *if attempts were made to involve industry in the rehabilitation process from the very beginning of it*.

This is not a far-fetched idea. A number of programs coordinating rehabilitation and industry are attempting to define and isolate the elements that result in successful and speedy placement. In 1970, the Department of Health, Education and Welfare provided funding for eleven model programs placing handicapped people in competitive jobs. Houseman and Smith (1973) describe the features of one such program developed at the Human Resources Center, a private, nonprofit organization located at Albertson, Long Island. The project was designed for the severely disabled client. The goal was to obtain 'entry-level, white-collar jobs' in the local business community. The first step taken was to construct the Center's training program so that it would resemble each company's on-the-job training programs as much as it possibly could. The rehabilitation staff had to work closely with a business advisory group to select and develop instructions and training equipment. The project tried to place the trainee on the job as quickly as possible with evaluation at the Center limited to eleven weeks. (This included instruction.) Each company assumed the responsibility for training the individual in the specific tasks of each job.

Over 300 clients were served in four years. Their ages ranged from 18 to 65 years. The disabilities included: paraplegia, quadraplegia, hemiplegia, cerebral palsy, cancer, blindness and many others. Of the 300, the program placed 220 in jobs. Over 10 percent of the 220 people had to be placed in more than one job so that placements really numbered around 245. Salaries ranged from $5,000 to $10,000 annually.

The methods of this program are of interest. In the first place, companies took part in it from the time of the first diagnostic interview, at which the client's capacity to accomplish basic job functions was ascertained. The vocational diagnostic interview was developed by the Minneapolis Rehabilitation Center (Sturm, Otto and Bakeman, 1972) and was used in the project continuously. The interview focuses on a specific job goal and determines what the barriers might be to its attainment. The rehabilitation counselor acted as liaison between clients and the industrial firms. Once a company agreed to participate, it appointed a 'company coordinator' to work directly with the rehabilitation agency staff. This enabled the counselor and the coordinator to combine their 'expertise' in a way that made job training more specific and placement more prompt. The two together filled job openings, arranged for interviews, shared interview results, placed the client and provided follow-up or follow-along services.

The eleven projects, of which the Human Resources Center program was one, are called Projects with Industry (PWI) and indicate the new productive relation that is developing between rehabilitation and industry. Both parties enjoy tremendous advantages from such an arrangement. In the case of industry, by involving itself early in job training and evaluation, it obtains a well-trained employee who has been exactly fitted to its work needs and who has already proved he or she can meet them. The rehabilitation facility gains by receiving specialized training equipment, industrial technical assistance, plus staff back-up.

Sears Roebuck, IBM, Metropolitan Life Insurance, Bankers Trust of New York and the U.S. Civil Service Commission, were only a few of the companies involved. In fact, nearly 500 private industries were involved, representing almost all facets of American business. The soundness of the program is evidenced in part by the fact that nearly three out of every four handicapped individuals served by the programs

were placed in the 'competitive labor market.' Also, the quality of jobs secured by the handicapped indicated that the PWI program was opening up new job opportunities for the disabled in career positions in such fields as computer technology, optical, technical and managerial areas (machinists, lathe operators, grinders and supervisors).

From July to December 1973, 1,063 employees were placed in industry out of 1,724 served. This amounts to 62 percent placement, a slightly lower rate than the year before, and yet far below the 75 percent rate reached in 1974. The cost per placement amounted to $1,000 as compared to a placement cost of $2,137 for the State/Federal vocational rehabilitation program. Earnings for the 1,000 clients in 1973 exceeded $5 million and at least $1 million in Federal taxes was paid so that, in effect, the program paid for itself.

There is no doubt that the PWI approach resulted in a higher placement rate than most traditional rehabilitation methods, industry saved the cost of training the disabled and the clients placed by this method were retained by industry because their training was specially tailored to industry's job needs. Industry also benefited from the free 'follow-along' services provided by the project or the State vocational rehabilitation agency to the handicapped, especially during the probationary period of work. The handicapped benefited because their job training was undertaken for a particular position. The handicapped also had a more direct access to some major corporations through the program and they had the opportunity to avail themselves of advanced training techniques and to demonstrate their capacities where it would matter.

Perhaps the expansion of a Projects With Industry kind of program is the type of thing which the severely disabled and other handicapped people most need. It must be emphasized that any first-rate rehabilitation-industry program ought to pay careful attention to severity of disability. The severely disabled in this country need help most and in most cases receive it least. Yet it is severity of disability that acts to keep people out of work. A survey done by Antonio Suazo of 200 workshops in 1972 concluded that the more disabled a person was the harder he became to place, and a study done of disabled veterans by HumRRo in 1974, concluded that even more than education levels, severity of disability was *the* major difficulty in trying to place clients in ordinary jobs. The new Rehabilitation Act of 1973 places emphasis on the severely disabled and their problems.

THE HANDICAPPED AND JOB SUCCESS

In the past, the burden for succeeding in an ordinary job was placed squarely on the bent shoulders of the handicapped person. When entering rehabilitation, he was told rehabilitation was not a thing that was to be done *to* him, but rather an improvement he must seek and make *for* himself. When it came to his job, he was told that its success depended on the way he applied himself, without being told that the way he applied himself might depend a great deal upon the attitude his company and his supervisors took toward him. The responsibility never went both ways. We are saying it should. In fact, the greater portion of responsibility for the quality of a worker's performance and morale lies with the company and not with the worker—a fact proven by scientific research. We all know that if we treat people as they are, they remain as they are; they are not expected to improve and so do not. But we know that if we treat people as being capable of much, they will begin to produce, not just what is expected of them, but sometimes much more. This is not a theory. The Kellogg Foundation did a study in 1971 and concluded that as the performance of students seldom rose above the expectations of their teachers, so the teachers seldom rose above the expectations of their administrators. Even more impressive research was conducted by Educational USA in 1967. In one study conducted at a school in San Francisco, it was found that if teachers thought a pupil had a high IQ, the expectation made itself come true—that startling improvements in the pupil's IQ actually occurred within eight months.

For the study, 20 students were presented to their teachers as being possessed of unusual academic ability. Eight months later, the 'gifted' children had gained 2.48 IQ points more than the remaining students of the same class. Yet they were not really gifted, having actually been picked at random. But believing them gifted, the teachers treated them as being so, and the children gained in intelligence and began to do gifted things.

Another research project took place in New Jersey and was entitled, 'Who Failed? A Study

of Subject Failure at the Secondary Level,' which confirmed that when a child failed, it most often had to do with the 'low expectations' of parents and teachers rather than with defects in capacity of his own.

Businessmen are usually impatient of this kind of research. They are practical men; the grounds they act from are business grounds. Their main concern is with the new measure that spares waste, the new road to greater wealth, with every instrument that diminishes the cost of production, every discovery that facilitates efficiency. And yet what is more practical than to have workers who do well, who are productive, who remain on the job and who feel satisfied because their work engages their deeper and more abiding feelings and interests? It is when people succeed in their work that they begin to have a real feeling for an interest in the nature of the work itself, rather than the extrinsic rewards of work such as pay, working conditions or fringe benefits. There is no greater tribute to company management than for it to have workers who have a proper love of their work, who out of pride or a sense of honor, seek to do well in it.

In our own time, we see people willing to battle to the utmost limit for the principle of self-determination, a fancy phrase which means merely that people are only happy in the service of aims that they themselves have chosen. While this idea may prove inconvenient, it is incumbent upon the business community to be able to accommodate it and, most importantly, to try and find out what it may mean to their business. Handicapped individuals and the business community may differ, but the differences of another's thought may fertilize and act to sharpen one's own.

Employers who have been attentive to their disabled workers have usually profited from it. Many employers, like DuPont, for instance, are successful employers of handicapped people, and have helped the disabled to reach that successful balance between what a worker wants from his work and what the work wants from the worker. At DuPont, for example, many disabled employees have remained on the job a long time and have advanced dramatically in salary and position.

So, it can be done.

CONCLUSION

Handicapped individuals have entered a new era, and nothing heralded it more loudly than the appearance of the Rehabilitation Act of 1973.

There *is* such a thing as a right to work, to freely choose one's work and to compete fairly for work one is able to do. Handicapped people were ignored by their country as a whole, and by employers and co-workers as a part of that country. Employers and workers are not wicked and handicapped individuals good. Both have occupied different circumstances, and it is those circumstances which have directed what has been done. Human nature is the same in all men. If a portion ever looks to be better, it is only because it has not been put to the same test.

What both sides should do now is to listen to each other—put themselves in the place of the other—for that is the only point of view that produces a sound understanding. It is the law and the courts are saying that the handicapped people of our country have a right to be able to do work they are fitted to do. That, in their right to earn their own bread by their own toil and to eat and enjoy it, they are the equal of employers and of anyone else.

ECONOMIC CONCERNS OF HANDICAPPED PERSONS

Awareness Paper Prepared By

Monroe Berkowitz, Ph.D.
Jeffrey Rubin, Ph.D.
John D. Worral, Ph.D.

TABLE OF CONTENTS

	Page
Economics and Handicapped Persons	219
Economics and the Mission of Conference	219
Employment, Transfers and Services	220
Plan of the Report	222
Definition and Counts	223
Programs and Support	226
Evaluation	230
Efficiency	230
Equity	230
Effectiveness and Adequacy	231
Some Evaluation Tools	231
Program Evaluation and the Consumer	232
Benefit-Cost Analysis and Social Investment	232
Some Problems in the Application of Benefit-Cost Analysis	232
Political Decision-Making and Benefit-Cost Analysis	233
Benefits and Costs of the Federal-State Vocational Rehabilitation Program	233
Federal-State Vocational Rehabilitation Program as a Social Investment	234
Potential Legislation and Impact on Handicapped Persons	234
National Health Insurance	234
Negative Income Tax	235
Nationwide Temporary Disability Insurance and No-Fault Insurance	236
Economic Issues for Conference Review	237
The Costs of Handicaps	237
Sharing the Costs	238
Expenditures and Choices	239
Summary and Conclusion	243

Economics and the Mission of the Conference

The Conference is designed (1) to stimulate a national assessment of problems faced by individuals with physical or mental handicaps; (2) to generate a national awareness of these problems and to develop recommendations for legislative and administrative actions, and (3) to allow individuals with handicaps to live their lives independently, with dignity, and with integration into community life.

As it considers policy recommendations designed to achieve these objectives (particularly number (3)), the participants at the Conference will necessarily have to consider economic matters. Our intentions in this background issue paper are to explore the basic conceptual aspects of an economic approach to the problems of handicapped individuals and to present background information, data, and analysis.

Economics is the study of how society's resources can best be utilized to make man better off.* Given this broad definition, it is evident that there is no single economic concern of the handicapped. Rather, several basic issues are at the heart of any economic analysis of handicapped individuals.

In a free society, it is generally accepted that each person is the best judge of his own well-being. One clear example of the validity of this notion is the ever-increasing participation of handicapped individuals in the resolution of issues affecting them as exemplified by the proportion of handicapped individuals at these conferences. Thus, for example, when we speak of dignity and independence, it is assumed that each person is the best judge of how these goals are to be attained.

Everyone finds it difficult to achieve the desired outcomes they have decided to pursue. The difficulty a person faces in attaining their goals, whether they be dignity and independence or some others, is magnified when a handicapping condition is present. Because the handicap, almost by definition, limits the choices open to a person, the likelihood is that the handicapped person will find extra impediments to successfully fulfilling his goals. Many people with handicaps have achieved dignity and independence (in some cases at great cost) but others have not.* For this latter group, it may be a combination of public programs is required if dignity and independence are to exist for all handicapped individuals. A substantial number of programs designed to assist handicapped individuals currently are in operation. Generally, immediate goals of these programs are more specific than the ones designated in the mission statement of the conference. These specific goals include the improvement of the employment prospects for handicapped individuals, the transfer of income (in cash or in kind) to handicapped individuals, and the provision of special services.

Before we consider these goals in greater detail, it is important to discuss the economics of the social context in which programs are begun, operated and changed. We recognize that any public program that entails the use of redistribution of society's resources will not be able to function for long unless a significant portion of the body politic is convinced of the wisdom of the activity in question and are able to make their demands known. There are two general circumstances that produce a situation where public support will most likely be forthcoming. The bases for most of government intervention in the functioning of the private sector economy are cases where private markets fail and situations where the distributional outcome of the private market is deemed undesirable. For most of the areas where programs exist for handicapped individuals either or both of these conditions are present.

Even though some rational economic argument can explain the establishment of the programs, additional effort is needed to evaluate the change programs, particularly if their effectiveness is in question. Because society is consistently attempting to utilize its scarce resources to improve overall well-being (of which only a portion is derived through handicapped individuals), it is important that the relative value of programs for handicapped individuals be identified and measured. *Clearly the chances of handicapped individuals achieving their goals are enhanced if they can establish that expenditures made on their behalf are justified and thus*

*It should be pointed out that great controversy surrounds the empirical measurement of society's wellbeing.

*More on this distinction will be forthcoming in our chapter on terminology.

provide the basis for continued and expended efforts on their behalf.

Employment, Transfers and Services

Dignity, independence and integration into community life are fostered for most of us through the means we use to fulfill various social roles. These means include participation in the labor force, as well as participation in leisure pursuits and activities in the home. Even though all 215,000,000 of us are not in the labor force, it is the output of a productive economy on which we all depend for our sustenance. Those who are not actively labor force members obtain a portion of society's output from some combination of family members, past savings, insurance, and public sector transfer and service programs.

A. *Employment*

Although definitional complexities are enormous, many of those who are judged as "handicapped" can successfully obtain employment under the right circumstances. Others who are handicapped are unable to overcome either the direct obstacle posed by their condition or the obstacles raised by factors outside their immediate control including discrimination, architectural and transportation barriers and lack of job information or the necessary skills.

Employment is not a necessary condition for someone who seeks to live with dignity and independence and be integrated into community life. Many nonhandicapped have achieved these goals without jobs. Examples range from students, to the aged to housewives.

Yet many handicapped individuals do not wish to be excluded from the labor force. For many employment is the means to achieving the previously stated goals, and for others, employment is an end in itself. Several questions deserve careful consideration by the Conference if the true nature of the role of employment in the life of handicapped individuals is to be understood and improvements made in their labor market status. These include:

Which handicapped individuals are working and how do they differ from the nonemployed handicapped individuals?

How is the work behavior of other household members affected by the presence of a handicapped member?

How many obstacles beyond the control of handicapped individuals be lessened? Are legal regulatory actions or cash incentives the most efficient means to reduce existing barriers?

What is the appropriate role for sheltered workshops?

What are the costs and benefits and to whom do they accrue when various public instruments are utilized to extend employment of handicapped individuals?

What are the policy changes that are necessary to stimulate and encourage employment?

B. *Transfers*

As noted above, some handicapped individuals need not work to achieve their goals. Many will play an important role in the household and receive intrafamily transfers. Others will find their financial problems partially overcome by their behavior in the past which resulted in savings and/or privately secured insurance protection against income losses.

The majority of handicapped individuals who are unable to work have a stake in the vast array of public and private transfer programs now in operation. Historically, such programs have arisen at different times prompted by quite dissimilar events. Workers' compensation is a product of the growing awareness of the toll of industrial injury in the 1900's. Most of the other transfer programs are products of the New Deal era and the Social Security Act, an event to which both income support and income maintenance programs can trace their origins. Those whose handicaps result from the negligence of others are the recipient of payments made under the tort system. And yet others with specific handicaps are able to benefit by programs which have a more narrow concern for those with particular impairments. The White House Conference has a unique opportunity to assess the total array of programs and make recommendations that will improve their functioning.

In any such assessment, one basic question that must not be overlooked is: How can transfer payment programs remain fair to all while achieving their stated objectives at the lowest possible administrative costs? Other questions of concern are:

Do present programs replace lost income and alleviate poverty among handicapped individuals to the desired extent, i.e. are they adequate?

What structural changes can be made to improve program operation?

How can transfer programs for handicapped individuals be integrated with a negative income tax plan?

With the number of recipients and costs of these programs growing at a rapid rate, we must ask where the limits are:

We will devote a portion of this background paper to a description of the present structure and function of transfer programs. Program rationale, level of financing in recent years, and likely costs in the near future are also subjects of analysis. We cannot be indifferent to rising costs. In a free society, these transfers will continue only so long as the body politic can be made to see the net value of additional increments of transfer payments.

C. *Services*

While cash transfers and employment income provide the basic sustenance to handicapped individuals, there is also a wide array of services available to them. Some of these services are specialized and apply only to those with particular impairments while others are available to all of handicapped individuals. Still other programs are a part of general services offered to the public of which handicapped individuals are but one of the groups to take advantage of them.

These services include counseling and guidance, medical and health services, employment services—including information about the employment market, training services, physical adaptation of jobs, removal of architectural barriers, communication barriers, affirmative action programs, and programs designed to lessen discrimination against handicapped individuals. Additionally, there is the indirect benefit to the handicapped that is the result of programs of research. The research covers widely different areas and deals with everything from development and testing of new prosthetic devices to methods of social organization of rehabilitation programs.

A substantial amount of resources is devoted to delivering these services to handicapped individuals. In later sections, we examine the aggregate expenditures on service programs. Also special emphasis is given to the equity and efficiency characteristics of the single most significant nonmedical services program—the federal-state vocational rehabilitation program.

Again, as in the cases of the employment and transfers, we find that the public and private sector interact to provide and produce rehabilitation services. However, in the area of services, possibly the relationships are a bit more complex. The public sector may provide certain services financed out of general revenues or specific earmarked taxes. Also the public sector may finance some services that are provided by the private sector. Thus, many of the services financed under the federal-state program of vocational rehabilitation are, in fact, produced by the private sector and purchased by the vocational rehabilitation agencies. Increasingly, a good portion of the medical and health services is financed under a public sector program, but for the most part, are provided in private hospitals by private physicians and other types of health practitioners. We will present in the background paper something of the relative importance of the sector divisions and some of the trends and possible combinations of the public and private sector that might be available in the future.

Along with the special nature of public-private sector activity in the area of services, a number of additional questions require consideration by Conference participants. These include:

Are the present services optimal? Do they produce the desired output at least cost or is there some better way to aid handicapped individuals?

Are the benefits of the services distributed equitably among handicapped individuals? For example, is the legislation requirement in the federal-state vocational rehabilitation for preference in services to the severely disabled appropriate?

What is the best mechanism for establishing priorities in how and for whom service dollars should be spent?

Given the importance of knowing how well services do what they do, we must ask how program evaluation can best be conducted. Of special interest will be the determination of and incentives for provider agencies to do a better job at evaluation.

A great number of questions have been raised here and elsewhere. Below we provide some essential background information that should be utilized in answering at least a portion of these queries. Additionally, we will present an economic interpretation of the facts and the use of methods of economic analysis. Yet our purpose in presenting information and analysis is not to answer the questions posed (and whatever others that are deemed appropriate) but to

provide sufficient material and data to provoke useful, stimulating and productive debate among the Conference participants. It is in this way that we can contribute the most to a Conference that successfully accomplishes its mission.

Plan of the Report

In the next section of the report, we will set forth some basic definitions derived from scholars in the field. The use of terms among researchers, practitioners, and the public is sufficiently confused to require special consideration. Although nomenclature is not the important thing, it will be shown that concepts are of fundamental importance in the formulation of rational policy.

In short, the following line of thought will be pursued. The current status of the people who are the focus of this Conference stems from any of several causes, each of which is essentially medical. Such pathological conditions may give rise to what we shall call impairments, which in turn may place certain limits on one or more of an individual's functions. If this series of circumstances leaves a person unable to perform his normal social role, we will classify the person as disabled. Thus, many Conference participants although severely impaired and limited would not be classed as disabled.

These terms are well accepted in survey and other research work should be understood by Conference participants. Less agreement exists on how the terms "handicap" and "handicapping" and "handicapped" are to be construed in light of the linguistic construct above. We shall attempt to make some headway in reconciling the confusion that persists.

Next we turn our efforts to a summary and explanation of surveys that aim at identifying and counting the disabled. Surveys are valuable because they enable the researcher to maintain a consistent set of definitions Such is not the case when we turn to transfer and service programs which have their own, and often, different definitions of disability. We will discuss the resulting problems and suggest reasons for this confusing approach to the provision of support for the disabled. Two major factors to be discussed are program objectives and the need for specific eligibility criteria. The confusion in defining, identifying, and counting the disabled is something that must not be ignored by the Conference.

In the following chapter we lay out the structure and functions of the present public and private mix of disability programs. Several reasons for payments will be introduced and programs will be classified accordingly. Estimates of the aggregate expenditures will be presented and some comments on the trends over time will also be noted.

Although there are very good reasons for a multiplicity of programs, the current structure is so complex as to become unmanageable and difficult to understand. By presenting this overview of programs, gaps and inconsistencies may be more easily identified and remedied if deemed appropriate. While it is important that these programs be satisfactorily integrated, there does not appear to be a good case for a single (or even a very few) program for the disabled.

As noted earlier, programs must face continued evaluation. In the next chapter we concentrate on the methods of program evaluation and show some examples of how economic principles retain their applicability in the disability context. It is essential that the competing demands for scarce resource by members of other groups in society be acknowledged. The tools of evaluation are one of the means at society's disposal to put these different programs on some level of comparability.

An equally important basis for evaluation is that it can be used as a measure of program handicapped) interests. The recipients of services place demands for better performance on programs. To objectively judge how well such demands are being met, some notion of the criteria of evaluation which would in effect mean a capacity to measure performance, must be presented.

The previous sections have been devoted largely to descriptive matters. What remains is a discussion of policy alternatives and a final comment on what we believe to be the most significant items and options that deserve a place on the Conference agenda.

Because of the nature of this paper and the limitations of space, we will not present an extended discussion on the implication for handicapped individuals of each of four major policy alternatives: negative income tax, national health insurance, nationwide temporary disability insurance, and no-fault insurance, We will discuss some of the likely first level impacts on handicapped individuals for each major program change.

Finally, we will draw all the facts, analysis, and inferences together and present issues for debate. We expect these to include but not to limited to: (1) the need for agreement on uniform concepts; (2) the significance of overall economic conditions on the status of handicapped individuals; (3) the need to measure the burden of handicaps and ways to share the resulting costs between groups.

We expect that the Conference may wish to pass a number of resolutions which necessarily must be phrased in a general way to accommodate the varying interests of the participants. At the same time, if the recommendations are to be effective, they must go beyond the call for the elimination of architectural barriers, discrimination in employment, higher levels of benefits and expended services. Acceptance of the resolutions and accomplishment of the Conference's mission will be facilitated if the recommendations could be coupled with some awareness of the financing, distributional, and other economic issues involved. It would be beneficial if the Conference would recognize that incentives to employers to redesign jobs, the provision of general job information services, and increased educational opportunities all have a profound effect on the ability of handicapped individuals to participate in the labor force and each has a cost.

In sum, we believe that the best way for the handicapped to achieve the goals set out in the mission statement of the Conference is to develop the mix of public and private support that will limit the obstacles handicapped individuals face while increasing the options from which they have to choose. Not all the obstacles can be eliminated nor can the number of options approach infinity, yet full recognition of the costs and benefits of alternative means of achieving these ends will enable society to use its resources more effectively in the future.

DEFINITIONS AND COUNTS

At times it appears that we all live in a "Catch-22" world where the same person is judged too disabled to receive rehabilitation services from one program and not disabled enough to receive benefits from another. If programs cannot agree on a single concept of the handicapped or the disabled it should not be surprising to see the same cloudiness prevail as we carve out concepts for purposes of counting the disabled or listing their characteristics.

We begin by viewing disability as the end result of a series of circumstances leading to an inability to perform any of the major life functions. The process begins with a disease or pathological condition which leads to an impairment of a "physiological, anatomical and/or mental deviation."* For example, the impairment may be the loss of strength due to deteriorated muscle tissue or the loss of a limb. Each suggests a deviation from standard biological structure or function. The impairment in turn may cause some limitation in physical or mental functioning which may be responsible, when considered with other factors, for a disability or an inability to perform in one's generally recognized social role. Confusion is apparent as attention is turned to determining where along these spectrum the handicapped are.

"Handicap" is often defined as disadvantaged. Certainly a disabled person meets this rather simple notion. But there are surely many of the functionally limited—non-disabled who are also physically or mentally handicapped. Also, many of the impaired who have no specific limitation might be judged disadvantaged as a result of their health. Someone who is unhealthy but is capable of performing the major physical functions would fall in this group. Epileptics who have only minimal, if any, functional limitations may be deemed handicapped. Someone with a pacemaker may be able to function perfectly well but his apprehensions of a heart attack may put him in the handicapped category.

These problems point up the broad interpretation often found for handicap. Until agreement can be reached on more specific usage of terminology we prefer the disability model described above. One initial attempt to clarify these concepts from a particularly economic perspective has recently been suggested.* Although Culyer, unfortunately, interchanges disability and handicap, his general line of thought is useful and worth commenting upon here. He argues that handicap is a subjective concept

*See Saad Nagi, "Disability Concepts and Prevalance" paper given at First Mary Switzer Memorial Seminar, Cleveland, Ohio, May 1975, for a more detailed discussion of the distinctions.

*See A.J. Culyer, "Economics, Social Policy and Disability" in D. Lees and J. Shaw, eds., *Impairment, Disability and Handicap: A Multidisciplinary View,* Heinemann Educational Books, London, England, 1974.

and depends upon how society views the individual in question. The determination as to whether or not someone is handicapped depends on a social assessment of the impact of the impairment on a person's welfare. The greater the impairment affects a person's options or life chances, the greater the cost to the individual. When these costs fall beyond the normal range of costs the individual is disadvantaged or handicapped.

If we maintain the definition of disability discussed above it is possible to bet some idea as to where this view of handicap falls. Perhaps everyone with an impariment is, to some degree, handicapped, for at least some period of time. The severity of the handicap may be viewed as varying with the costs which in turn have, for the most part, a direct relationship to the series of circumstances concluding with a disability. An impairment may have only minor impact on a person's options, whereas a functional limitation will likely more severely limit options and finally a disability may be even more "costly." Even within disability it is possible to consider many as more severely disabled than others, possibly by reference to chances for successful rehabilitation or by considering whether they are disabled in more than one activity. The size of the costs and the implied severity of the handicap have a great influence on the form programs take.

We begin now to look at the results of several surveys of the disabled population. The first set of results we present are derived from reports by the Social Security Administration concerning the data generated by the Social Security Survey of the Disabled: 1966.* For survey purposes disability was defined "as a limitation in the kind or amount of work (or housework) resulting from a chronic health condition or impairment lasting three or more months."† It must be stressed that only the work-housework function is examined. Thus, those able to work but limited in other pursuits or aspects of life are not incorporated in this study. The survey found that 17.8 million people of the noninstitutionalized population between 18 and 64 were disabled for longer than six months in 1966. The total included 6.1 million persons (5.9% of the population) classified as *severely disabled,* i.e. unable to work regularly or unable to work at all. Of this group 3.7 million or 3.6% of the population were unable to work at all. Five million persons (4.9% of the population) were occupationally disabled, defined as being unable to work at the job held prior to onset or unable to work full-time; and 6.6 million persons (6.4% of the population) had *secondary work limitations,* defined as able to work full-time regularly, but with limitations in the kind or amount of work they could perform.

While it is true that these concepts may not fully capture the population with which the participants of this Conference are concerned, it is true that the notion of disability used in the Social Security survey is rather inclusive. Therefore it will prove valuable to explore somewhat more deeply the characteristics of the disabled.

In the model presented above, the nature and severity of the physical and medical condition is greatly responsible for determining whether or not someone becomes disabled. Also, the conditions tell something about the chances of preventing the disability as well as providing useful information regarding the appropriate methods to reduce the cost burden of the handicapped. For these reasons we begin describing the characteristics of the disabled by summarizing the findings of the survey as regards the disabling conditions found among the disabled.*

Among the disabled, musculo-skeletal disorders (diseases of the bones and organis of movement) and circulatory conditions were reported as the major disabling condition in 30.9% and 24.8% of the cases, respectively. The majority of the remaining disabled reported conditions in one of the following four groups: allergic disorders (10.8%), disorders of the digestive system (7.2%), mental disorders (6.3%) and nervous system disorders (5.2%).

If we examine the disability rates per 1,000 persons in the noninstitutionalized population,

*The survey findings are found in a series of reports published by the SSA in the late 1960's and early 1970's.

†Lawrence D. Haber, "Identifying the Disabled: Concepts and Methods in the Measurement of Disability," Report No. 1 from *Social Security Survey of the Disabled: 1966,* U.S. Department of HEW, SSA Office of Research and Statistics, December 1967, p. 6. Results are reported for individuals disabled longer than six months.

*We summarize the findings presented in Lawrence D. Haber, "Epidemiological Factors in Disability: I. Major Disabling Conditions," Report No. 6 from *Social Security Survey of the Disabled:* 1966, U.S. Department of HEW, SSA, Office of Research and Statistics, February, 1969.

we find that these rates grow rapidly by age. For example, the rate for circulatory disorders goes from 17.1 for those aged 18 to 44 to 57.9 for those 45 to 54 to 120.7 for those between 55 and 64. The overall rate was 172.2 with overall rates by age groups (in the same order as above) being 102.1, 231.1 and 361.6. The growth in the disability rate "was largely due to increases in the disabling effect of the conditions."* but in some cases (arthiritis and heart disease) the rate change is a result of higher prevalence rates. In general, Haber found that age rather than major disabling condition was a better predictor of the likelihood of disability.

Perhaps more important than the disabling condition in the assessment of a health problem is the impact of this impairment on the individual's capacity to perform certain functions. Thus, even though a person may be impaired he may be able to do everything he could before his condition changed. We summarize below the findings reported by Haber on functional capacity limitations.†

One purpose of obtaining information on activities such as physical capacity, mobility, self-care and sensory capacity is to determine how the inability to perform certain functions affects work and daily living performance. Haber notes: "Limitations in the ability to perform any of these activities would generally constitute some barrier or handicap to effective role performance."‡ It was not possible to assess all the limitations that arise from impairments. A number of the disabled show no limitation as measured by the survey instrument. In the survey 72.8% of the disabled had an activity limitation such as walking, lifting and using stairs, only 7.1% of the disabled needed help with personal care activities, 10.4% had mobility limitations and 23.0% had vision, hearing or speech limitations. In general the data on limitations was a much better predictor of severity of disability than impairments.

A second source of data on the disabled population is the National Health Survey. Disability is defined as "any temporary or long-term reduction of a person's activity as a result of an acute or chronic condition."* For our purposes, the most significant classification is between levels of chronic activity limitation. These three categories are:

1. Persons unable to carry on major activity for their group. In this context major activity refers to ability to work, keep house, or engage in school or preschool activities;
2. Persons limited in amount or kind of major activity performed;
3. Persons not limited in major activity but otherwise limited.

On the basis of these definitions the NHS identified 12.7% of the civilian, noninstitutionalized population (all ages) as having some form of activity limitation as a result of chronic diseases or impairment in 1972. The breakdown among the degrees of limitation are: 1) Unable to carry on major activity, 3% (6.0 million); 2) Limited in amount or kind of major activity, 6.6% (13.6 million); 3) Limited in other activities, 3.1% (6.3 million).

Along with the data on activity limitations, additional information was collected on individuals with mobility limitations. In 1972, 3.2% of the population had a chronic mobility limitation and 92.3% of these had an activity limitation. As with activity limitations the percentage of the population with a mobility limitation rises with age, to the point where 17.6% of those 65 and over had a mobility limitation due to a chronic condition.

If we turn to the chronic condition causing the activity limitation, heart conditions are the leading factor in 13.4% of the cases, arthritis and rheumatism, 11.2%, impairments of lower extremities and hips, 5.9% and impairments of back or spine, 5.8%. For mobility limitations, arthritis and rheumatism account for 22.2% of the cases with impairments of lower extremities and hips accounting for 10.8%, heart conditions 8.7%, cerebrovascular disease 6.3% and paralysis 4.4%.

Additional information on the disabldd is available in other Social Security publications as well as in other reports from the National Health Survey. Also, the Bureau of the Census

*Ibid., p. 10.

†L.D. Haber, "The Epidemiology of Disability: II. The Measurement of Functional Capacity Limitations," Report No. 10 from *Social Security Survey of the Disabled: 1966:* U.S. Department of HEW, SSA, Office of Research and Statistics, July, 1970.

‡Ibid., p. 3.

*See for example Charles S. Wilder, "Limitation of Activity and Mobility Due to Chronic Conditions," Data from the *National Health Survey*, Series 10, No. 96, U.S. Department of HEW Washington, D.C. (November, 1974), p. 51.

surveyed the disabled population in 1970 and Saad Nagi of Ohio State is preparing the results of yet another survey of the disabled. The Social Security Administration has several new surveys underway or completed including one on the recently disabled. Finally there are numerous larger surveys where the disabled are but a subset of the population allowing for excellent comparative studies. Two of the major works in this category are the Michigan Panel Study of Income Dynamics and the Ohio State National Longitudinal Surveys.

PROGRAMS AND SUPPORT

At present a substantial amount of society's resources are devoted to aiding handicapped individuals. A variety of programs have been developed to funnel both the cash and services to handicapped individuals. In this section we review the types of assistance available, the basis for their existence, the specific nature of several major programs and estimates of the aggregate expenditures.

Numerous public and private programs converge in their support of the disabled. Some programs such as the Social Security Disability Insurance program (DI), SSI, Workers' Compensation and Vocational Rehabilitation serve only the disabled. Other programs, including for example food stamps, general manpower training plans, AFDC, and unemployment compensation, serve the disabled as well as the non-disabled.

We want to classify both sets of programs in several ways. First, we classify them according to the rationale or reason for payments.* The bewildering number and variety of programs begins to make more sense as we realize each exists for different reasons. We do not argue that the structure is wholly rational and that it cannot be improved, but only want to recognize that programs have different announced reasons for being.

In the first category are the various social insurances, the government plans under which individuals are required to contribute to a program that guarantees the continuation of a portion of the person's income stream in the event of certain contingencies; in our case the chance of a health condition leading to a disability. Eligibility is directly contingent to contributing status and their essential purpose is to maintain the income of those whose income stream is interrupted due to disability. In part also they provide a floor below which income is not allowed to fall. The Social Security Disability program, Workers' Compensation, the several state and railroad temporary disability plans and Medicare are some of the major programs classed as social insurance.*

In the second group of programs payments are based on not only disability but veteran status as well. The major programs include the veterans' compensation and pension programs along with the medical and various support services that are available.

The third group we label as risk aversion. It includes group and privately secured insurance including the formal sick leave and disability provisions of the retirement agreement between employer and employee. Payments are made for many of the same contingencies as in the social insurances, but the individual must have anticipated the contingency and made premium payments because of the desire to spread the risk. In certain programs, the payments of premiums are made on his behalf while in either case, the payments are made voluntarily and without governmental compulsion. An important aspect of risk aversion programs is that they are responsible for a good deal of the difference in treatment accorded the disabled. This is one area where income, tastes for risk and pre-disability situation each enter into how the cost burden of a handicap is shared.

In the income support category, we include those programs designed specifically toward alleviating the poverty-stricken group of handicapped persons. These programs provide a last

*More detailed information on these matters can be found in Berkowitz and Johnson, "Toward an Economics of Disability: The Magnitude and Structure of Transfer and Medical Costs," *Journal of Human Resources*, 5 (Summer 1970) and in M. Berkowitz, J. Rubin and J. Worrall, *An Economic Evaluation of Disability Programs*, forthcoming.

*We note here that much of the aggregate data to follow includes short-term disabled, a group not often deemed handicapped since their condition will disappear over time. Thus as an estimate of expenditures on the long-term handicapped our numbers are clearly an overestimate. The area where this problem is most significant is in health care programs where we sought to include all non-routine expenditures. In this way we include most who receive care and are unable to work (i.e. disabled). But a narrower focus on only those who could expect to have their impairment last a long period would generate lower figures.

resort for those who "fall through the cracks" and miss the eligibility conditions of other programs. Income support programs include both cash support, such as SSI and AFDC, and in-kind plans such as food stamps and Medicaid.*

A person's disabling condition may be held to be the fault of others. In such cases the indemnity group of "programs" provides for payments. These are largely private sector payments arising out of tort cases where negligence can be shown. Automobile, malpractice and personal injury cases are the prominent examples. Growing dissatisfaction with this group has led to the enactment of no-fault legislation.

A final group of other programs is a potpourri of direct service programs and largely defies classification as to reason for payment. The most significant of the programs here is the federal-state vocational rehabilitation program which is based upon a human capital investment theory.

We have sought to aggregate expenditures related to the disabled including short-term as well as long-term disabled although we were able to identify over 80 programs, we have undoubtedly overlooked some, particularly in the state-local and private direct service category. Our look at these areas leads us to suggest the figures reported below, while an understatement of the total, represent a lower bound not far from the "correct" figure.

In sum, we estimate the public and private expenditure in 1973 on the disabled to be $83.1 billion, a large figure indeed. Slightly over half of this figure or $46.6 billion is in the form of medical care or payments. For example, a two-week hospital stay, paid for by an insurance carrier, is included because the person clearly met the definition of disability, that is an inability to perform in his normal social role. Yet, even if only a quarter of the payments would be classed under disability or the handicapped if a stricter long-term based definition were utilized, the total would remain in the area of $48 billion, certainly not a paltry sum.

Transfers accounted for $34.2 billion, with somewhat less than a third being in the private sector. The private sector transfers include sick leave, disability insurance payments, and automobile, malpractice and other bodily injury plans. Services accounted for the remaining $2.3 billion. The public share was 63% or $52.3 billion.

If we turn to how the money was spent in the different program categories some interesting results are apparent. In 1973 the percentage breakdown was as follows: risk aversion–35%; veteran-status–10%; social insurance–23.6%; indemnity–7.1%; income support–22.6%; and other–1.7%. Over 80% of all the expenditures are in the risk aversion, social insurance and income support categories.

If we cross-classify the results we find much less variation across categories in the cash transfers than in the medical payments. The results show that insurance or risk aversion and income support each are a much larger relative share of medical support, 47% and 27%, respectively, than they are of transfers, 24% and 15%, respectively. On the other hand, status and indemnity are significantly better represented in transfers, 15% and 17%, than they are in the medical group, 6% and 0%, respectively.

Before examining the nature of several major public programs, we turn to considering how the transfer and medical expenditure levels changed between 1967 and 1973. Substantial growth is apparent and is the result of several factors. These include the growing numbers of disabled people, liberalized eligibility requirements, and increases in aid per recipient. If we hold constant that portion of the rise accounted for purely by inflation, we still find that transfer and medical expenditures rose by 54% between 1967 and 1973; the transfers by 47% and the medical payments by 59%. Each of these trends along with the basic breakdowns by type and nature of program provides valuable descriptive information that can be used in debating the priority areas for increased spending. To get a better idea of the mechanisms by which much of this money was placed in the hands or spent on behalf of the disabled, we shall summarize the key components of several major programs. We proceed rather succinctly, assuming the participants have at least some general knowledge and familiarity with most of the programs.

*The basic criterion that was used to determine whether or not to allocate a portion of expenditures for those programs where disability was not a direct eligibility factor was whether or not the disability resulted in the condition on which eligibility depended. Thus a family receiving food stamps with a disabled member in the household would theoretically be included in the allocation of a part of the food stamp budget to disability. Of course the existence of cases where the family would be receiving support regardless of the disability means our estimate is slightly inflated.

The single major public transfer program for the disabled is the Social Security Disability Insurance program. Payments are made to covered persons who have a physical or mental impairment that has lasted, or is expected to last, 12 months or more and who, as a result of this impairment, are unable to engage in substantial gainful employment. There is also a program of payments to widows of covered workers who become disabled within seven years after the death of the covered workers.

Payments are made out of a special DI trust fund with money raised through a payroll tax of equal amounts on employers and employees. The trust fund also supports vocational rehabilitation efforts for those recipients for whom there is a chance of being restored to the labor force. Recent studies have shown that these efforts lead to a reduction in trust fund outlays and an increase in payroll tax contributions which together are somewhat larger than the cost of providing services.

In fiscal 1975 cash benefits from the DI trust fund totalled 47.6 billion, a rather large increase from the 46.2 billion that was expended the prior year. There were 3.9 million beneficiaries as of December 1974 and this had grown to 4.2 million as of August 1975. With payments in latter months totalling $783.5 million we find an average payment of approximately $187 a month.* The average benefit awarded during September 1975 was $241.37 per month for a disabled worker.

Two difficulties the program faces are its long-run financial status and the administration of the disability determination process. At the current rate of growth for expenditures and receipts the trust fund will have to draw down on its reserves, a result that signals the need for a change. One current proposal would raise the tax rate. An alternative, using general revenue taxes, has been suggested but not yet implemented. A positive aspect of such an approach would be the decreased reliance on a regressive payroll tax and a shift to the progressive federal tax structure. But a shift of this nature would alter the basic social insurance character of the program, something advocates of the payroll tax approach believe will weaken support for the program.

The determination of disability is a complex process allowing for several appeals before a person can finally be denied benefits. The rate of reversal by administrative law judges has been large and a subject of some concern. Efforts are being made to be more specific as to how occupation, residual skills, available jobs and other factors should enter into disability determination.* The Conference participants should give some thought to the appropriate means of defining disability with an eye toward the cost impact of either liberalization or further restrictions of the current approach. A particular concern will be what happens to and what assistance is available to the denied DI applicants. An adequate backup income support system, possibly a negative income tax, would go a long way in allowing DI administrators, to maintain a strict interpretation of disability.

The new Supplemental Security Income (SSI) program, effective as of January 1, 1974, involves direct cash payments to the aged, blind or totally disabled person who meets certain income and resource requirements.* The program is basically one where the federal government provides a minimum support that states may supplement. SSI recipients who would have been better off under AB, APTD and OAA must be supplemented by the states but new eligibles

*Data and information sources for DI and other programs are too numerous to list. Some major sources are the monthly Social Security Bulletin along with its Annual Statistical Supplement, The Catalog of Federal Domestic Assistance, the Appendix to the U. S. Budget, Veterans' Administration Annual Report, Life Insurance Fact Book, Sourcebook of Health Insurance Data and numerous books, articles and Congressional reports. One particularly valuable source is the Directory of Federal Programs for the Handicapped, compiled by Edward Klebe which can be found in the Congressional Record–Senate,, January 29, 1974, S613-S621. Also see *Handbook of Public Income Transfer Programs*, Paper No. 2 in Studies in Public Welfare, Staff Study for Subcommittee on Fiscal Policy of the Joint Economic Committee, October 1972.

*Three sources of information and analysis of the appeals process are Dixon, *Social Security Disability and Mass Justice*, Praeger, New York, 1973; The Committee Staff Report on the Disability Insurance Program, House Ways and Means Committee, July 1974, U. S. Government Printing Office, Washington, D. C.; and Research and Statistics Notes, HEW, SSA, Office of Research and Statistics, "Appeal of Disability Decisions," Note No. 3–March 1975.

*SSI is reviewed in the following two sources: *The New Supplemental Security Income Program–Impact on Current Benefits and Un-Resolved Issues*, Paper No. 10–Studies in Public Welfare, Staff Study for Subcommittee on Fiscal Policy of Joint Economic Committee, October 1973; and James R. Storey, "The New Supplemental Security Income–Implications for Other Benefit Programs," *Policy Sciences*, V. 6, 1975, pp. 359-374.

need not be so covered. The federal government will administer the supplements in the states wish.

In September 1975, the total federal payments plus the federally administered state supplementation (29 states plus the District of Columbia have opted for federal administration of their supplements) totalled $263.2 million for the disabled and $16.7 million for the blind. State administered supplementation for July 1975 (the latest month for which data is available) was $6.3 million for the disabled and $296,000 for the blind. The number of persons receiving federally administered payments as of September 1975 were 1,854,545 disabled and 73,875 blind.

The average monthly payments of September 1975 for the disabled in those states where there are federally administered supplements ranges from $197.54 in California to $95.93 in Kansas.* For the blind the range is from $211.02 in California to $108.76 in Montana. Calculations for an earlier period revealed that although SSI was likely responsible for a significant rise in the mean payment level, the program had not significantly reduced the variance in average payments across states.

In discussing SSI there are several areas where one may wish to consider the implications of specific choices on the disabled. For example, the definition of disability presently used parallels the one used in DI. How eligibility is determined also rests on a decision about the relative needs of the handicapped. Those who meet a strict disability definition are eligible (on the condition characteristic) for assistance while those rejected for the program must find other means of support. The costs of extending SSI to a broader population must be estimated and weighed against alternative uses of these funds. Information on what is happening to denied SSI applicants would be very helpful in this regard.

Along with the decision to expand or contract the program, there is the necessity of deciding the income requirements and support levels. The basic payment to people with no income and the treatment of earned and unearned income should be established with an eye toward meeting basic needs and maintaining incentives to find employment, where feasible. Thus, the rate at which the SSI payment is reduced as income goes up will tend to encourage or discourage, depending on the rate, SSI recipients from seeking employment. The treatment of unearned income, for example, from DI or the Veterans' Compensation program, should be carefully structured so that changes in one will not be offset by equal declines in SSI leaving the person no better off.

Two major programs are the Veterans' Compensation and Pension plans. The former covers service-connected disability while the latter is directed toward veterans with non-service connected disability. The calculation of support in the compensation program is based on percentage impairment determinations. A medical review establishes the percentage of disability based on an estimate of the affect the condition would have on earning capacity. Thus there is no means or work test. For each percentage disability a table is consulted where the monthly payment is given. As of August 1975, for example, a veteran with a 10% impairment and no dependents would receive $35 per month with the amount rising to $364 per month for 90% and $655 for 100%.

The pension program is for veterans with limited resources and a non-service connected permanent and total disability. Attainment of age 65 is taken as proof of total disability. For those below 65 the percentage impairment necessary to qualify varies with age. The amount a person will receive depends on income and assets rules.* Effective January 1, 1975, for a qualified veteran with no dependents and annual income below $300, the monthly pension is $160. For those veterans with an annual income of $3,000 the payment is $5 per month.

The combined programs paid out over $4.6 billion in 1973. Separate payments are made to survivors in cases of death. Also, numerous other forms of services are available to veterans including education assistance, medical care, voca-

*This discussion is limited to the states with federally administered supplementation because the combined figures for average federal and state payments are not available in those states that have chosen to administer their own supplements.

*Many sources exist for further information about these programs. See, for example, the Veterans' Administration Annual Report; Levitan and Cleary, *Old Wars Remain Unfinished*, Johns Hopkins University Press, Baltimore, 1973; *Those Who Served*, Report of the Twentieth Century Fund Task Force on Policies Toward Veterans, New York, 1974; Lindsay, *Veterans' Administration Hospitals*, American Enterprise Institute for Public Policy Research, Washington, D. C., 1975; and Research and Statistics Notes, HEW, SSA, Office of Research and Statistics, Notes No. 7 and No. 18, 1975.

tional rehabilitation (including subsistance allowances) and payments to assist disabled veterans to purchase specially adapted housing and autos.

The question of separate programs for veterans and non-veterans should be a topic for debate. Particularly in the area of income support type plans such as SSI and Veterans' Pension there would appear to be substantial duplication of effort. Also, consideration should be given to the impact of the shift to a voluntary armed forces on the need for treating veterans distinct from other public employees. It is true, though, that it may be necessary to offer substantially better disability protection to servicemen if sufficient numbers are to be encouraged to volunteer. Finally the impairment based calculation on which benefits are determined may mean that substantial resources are going to impaired, non-disabled high income veterans. Of course, changing the basis for payment would mean an income test to establish actual impaired earning capacity and perhaps veterans should not be subject to that procedure.

Numerous other programs exist, each with its own special nature and quirks. Space and time do not allow us to elaborate on each of them. An earlier footnote cited several excellent sources of general background information and data for these programs. For many there are a variety of analytical studies the reader may wish to review. If the Conference focuses more on the aggregate needs and status of the handicapped, many of the intricacies of individual programs can be overlooked. But as we begin to restructure programs to attain new goals more efficiently and equitably it is the very specific aspects of program design that require attention.

EVALUATION

We are interested in the evaluation of programs designed to assist handicapped individuals. Are programs "good" or "bad?" Should they be scrapped or expanded? Is a program meeting its goals or objectives? Evaluation can help us to answer some of these questions. While evaluation may not give us all the answers it will provide us with the framework necessary to make sound decisions. We cannot assume that a program is "good" because it has worthy objectives in the eyes of some. Nor can we necessarily condemn a program which denies service to those whom we deem eligible. In order to judge a program we should know something about its efficiency, equity, effectiveness and adequacy. The purpose of this chapter is to provide a framework for arriving at sound decision criteria for a successful social policy.

Efficiency

We may examine efficiency from several perspectives. A universal goal is to achieve the maximum benefit that can accrue from the use of society's resources. One definition of efficiency is that an efficient allocation of resources has occurred when there is no possible reallocation of resources which can make someone better off without making another worse off.

Another perspective on efficiency arises from the explicit statement that society's resources are limited. We cannot produce everything we desire; we cannot have all the programs that we want. An efficient use of resources occurs when we produce the maximum amount of goods and services possible with a given level of resources, or when we are using the least amount of resources possible to produce a given level of goods and services. This latter perspective is the more easily applied in program evaluation. It is unequivocable that anytime we can produce the same level of goods and services at a lower cost, we will have efficiency gains by doing so.

The ease with which we can evaluate the efficiency of the various programs varies with the nature of their output. Programs which have outputs that are measurable in some physical sense are easier to evaluate in terms of efficiency than those programs which do not.

Efficiency is an objective concern. We examine the effects of the allocation of resources on the level of output. But we are also interested in who receives the output produced and consequently in the distribution of goods and services.

Equity

Questions of what is equitable are subjective. As a society we make value judgments about what *ought* to be, and we often formalize these value judgments into the law. For example, we have decided that those individuals who are

most "severely handicapped" should have priority in the receipt of vocational rehabilitation services and we have formalized this constraint on the rehabilitation program and placed it in the statute. The rehabilitation program must now pursue its efficiency goal subject to such an equity constraint.

The introduction of equity constraints may lead to a diminution of physical output. In other words, we may value the gains arising from what we perceive to be fair treatment of the handicapped as more important than any possible inefficiencies which arise from that treatment.

Reasonable people differ as to what constitutes fair treatment or how equity is defined. However, we can derive some notions about how society views equity considerations from those which are already manifest in our laws. Two notions of equity which are important are horizontal equity and vertical equity. Horizontal equity usually refers to the equal treatment of equals. For example we would like two people with the same income to pay the same level of taxes but there are grave problems in determining when two people are equals and what constitutes equal treatment. Vertical equity refers to unequal treatment of unequals.

As an example, suppose that one individual suffered a disabling injury during the year and spent three thousand dollars for medical expenditures, whereas a second person with identical income escaped this misfortune, would we want the disabled person to bear the same tax burden? Vertical equity considerations may dictate a lower tax payment for the person with the extraordinary medical expenses and our federal taxes are structured to reflect this value judgment.

Programs can be evaluated in terms of who receives their benefits and who pays for them. But there is little agreement about who should pay for programs. One point of view is that those who benefit should pay. Another point is that public programs and expenditures should lead to a more equal distribution of income. Although there is not unanimity of opinion on proportionality vis-a-vis progressivity, there is little quarrel with the proposition that regressivity is undesirable, i.e. the poor should not pay for the services of the rich. Similarly, the judicial and legislative branches of our government have formalized our wish that differences in age, race, sex, etc. be ignored in the determination of who is equal.

Effectiveness and Adequacy

We want to know how effectively a program is meeting its goals. Suppose that the only goal of the rehabilitation program were to rehabilitate 300,000 people. We could then say that the program was effective in the sense that it was meeting its goal if the record showed 300,000 rehabilitants. It should be noted that a program may be effective and inefficient, or efficient and ineffective. An efficient program is more likely to achieve its goals but may not have sufficient resources to do so.

Similarly, a program may be efficient without being adequate, and effective without being adequate. Adequacy refers to the ability of a program to meet the needs of the entire population in a problem area. Suppose we designed a program with a stated goal of training one thousand mentally retarded citizens in vocational skills. If we found that the program was training one thousand citizens a year we would say that it was an effective program. But if in fact it could be shown that a population of 20,000 mental retardates were awaiting vocational training, we would not consider it adequate to meet the demonstrated needs.

Some Evaluation Tools

Some of the standard measures of program evaluation are designed to consider the impact of the program on the distribution of income, the tax burden it generates and who bears that burden, the benefit-cost ratio of the program, and the net number of people it removes from poverty.

If we wanted to evaluate a transfer program, for example, we might begin by examining the inequalities in the distribution of income before the program and after the program. We might also calculate the number of people who were raised above the poverty level by the receipt of program transfer payments. In addition to such distribution measures we would attempt to insure that the transfer payment program was being administered as efficiently as possible, i.e. at the lowest possible cost.

In a service program such as the vocational rehabilitation program, we might see which income groups benefit directly from the program, and which income groups pay for the program. Dr. Donald Bellante has done so for

the Florida federal-state vocational rehabilitation program. He found that the clients of the program were more frequently from the lower income groups whereas the tax burden of the program fell more heavily on higher income groups.* In effect the program generated net transfers which were inverse to income. This would be considered by many to be a desirable property of the program.

Program Evaluation and the Consumer

Program evaluation can provide valuable information to consumers by specifying who receives what services and who pays for them. If Bellante's findings are correct we probably are more willing to support the vocational rehabilitation program because it makes positive transfers to lower income classes. Popular support for the program may lessen if it were found that the tax burden fell most heavily on the lower income classes and that the higher income classes received most of the program's expenditures.

We place different values on equivalent services received by different categories of people. It may be important for us whether a program serves the severely handicapped, the moderately handicapped or the mildly handicapped. Program evaluation can make specific who is being served and hence form the base for recommendations for change incorporating new or different equity constraints.

The disabled consumer obviously should have an abiding interest in program evaluation. His self-interest dictates that programs be run as efficiently as possible and the more information about programs and services the disabled have, the better able they will be to use them to their full advantage.

In a free society, increased or continued expenditures on disability programs will be forthcoming only as society sees the value of those programs. Program evaluation if often a potential vehicle for making just such a demonstration. The use of benefit-cost analysis in program evaluation is a good example of this point.

*Donald M. Ballante, "A Multivariate Analysis of a Vocational Rehabilitation Program," *Journal of Human Resources* 2 (Spring 1972), p. 241.

Benefit-Cost Analysis and Social Investment

If society wants to allocate its resources efficiently, it is obvious there are many claims on resources and many social investments which could be made. Which of these investments to make is easy to describe theoretically, and difficult to decide objectively in the real world. If the basic goal is to maximize social well-being, we should choose those social investments which make the greatest contribution, given our resource constraints. Ideally we would invest until that point where the incremental social benefit of the last project or social investment undertaken is equal to the incremental social cost entailed in the resource use.

Benefit-cost analysis is a technique to assist in determining which investments contribute the most to our social well-being. The method incorporates an attempt to compute all of the benefits of an investment and to compare them with all of the costs of the investment. Those projects which have ratios of benefits to cost which are greater than one are eligible candidates for funding. Those with ratios less than one would not be undertaken because they would always cost more than their value to society. In order to determine which social investments should be undertaken first, we would rank order projects by benefit-cost ratios. We would then select those with the highest ratio of benefits to costs until we exhausted our investible resources. If individual projects were perfectly divisible, we would allocate resources among the investments such that the return per unit of resource invested would be the same for all projects.

But as one can imagine there are many problems which arise when one applies benefit-cost analysis to social investment. We examine some of these in a non-technical fashion now.

Some Problems in the Application of Benefit-Cost Analysis

One of the major difficulties is the quantification of benefits and costs. Some benefits and costs are unmeasurable by any concrete yardstick. If a severely handicapped person is provided a service that assists that person to accomplish an activity of daily living (feeding oneself), we know that the satisfaction of increased independence exists. But we do not

know how to assign a value to that gain. Similarly, there are benefits and costs which are external to the program which are real but practicably unmeasurable. For instance, the fact that over 250,000 people were assisted by the federal-state vocational rehabilitation program in achieving their goal of employment generates not only direct benefits to them through their participation in the labor market, but also indirect benefits to other citizens who will share in their physical and psychic productivity. Analogous cases could be presented for costs.

Another problem in benefit-cost analysis is that the returns from social investment flow over time and since we cannot foretell the future we are uncertain about future investment yields. In addition, if benefits accrue over a period of time, we must find a technique to discount the receipt of future benefits. The value of a dollar received today, barring deflation, will be worth more than a dollar received at sometime in the future. We must select a social rate of discount which reflects society's true time preference. If we do not, we can alter the correct balance between public and private investment.

Generally, we are striving to maximize social welfare when we undertake social investment but since we cannot explicitly measure social welfare, we frequently substitute national income or gross output. This substitution can lead to distortions especially if continued growth is not synonymous with increased well-being.

Political Decision-Making and Benefit-Cost Analysis

Although there are many other factors that should be considered before using benefit-cost analysis, space limitations dictate our mentioning only one. Political constraints on what can and cannot be undertaken weigh heavily in decision-making. Benefit-cost analysis in its present state cannot quantify equity concerns and political value judgments so as to integrate them into our valuation of benefits and costs. Consequently, decisions on social investment are made in a moral, ethical and political framework. Benefit-cost analysis is only one aid to decision-makers. It will not be the only input nor should it necessarily be.

Whether benefit-cost results are favorable or unfavorable for a specific project, society stands to profit by the information gained. If the project has a low benefit-cost ratio we may gain by transferring our resources to other uses which will more profitably serve us all. If the benefit-cost ratios for a particular project or program are high, we may use this favorable result in our quest for funds for the program. Benefit-cost ratios have been computed by many researchers for the federal-state vocational rehabilitation program. The ratios, despite different assumptions, time periods, data sets, etc. have usually been greater than one, and often significantly higher than that. We shall examine one such set of ratios as an example.

Benefits and Costs of the Federal-State Vocational Rehabilitation Program

A. *Benefits*

The chief measurable benefit of the vocational rehabilitation program is the increase in output that can be expected from the productive activity of rehabilitants. Wages, which are the usual measure of an individual's contribution to output, are compared at entry and at closure to determine if the program has increased the client's productivity.

The wage that a rehabilitation client was earning when he entered the program, if any, must be extrapolated over the client's life and discounted by the appropriate rate of interest. A similar extrapolation must be made for the wages that a client earns after completing the program. Both of these wage streams must be adjusted to reflect the probability of unemployment, injury, and mortality, and to account for the growth in the productivity of the labor force over time.

A recent study of the vocational rehabilitation program used the earnings experience of cohorts of rehabilitation clients with similar characteristics to project wages over the expected life of a client. Those clients with no wages at opening were assumed to have potential earnings, in the absence of rehabilitation, which were equal to those who were not admitted to the rehabilitation program.*

**An Evaluation of the Structure and Functions of Disability Programs*, Year 1 Summary REPORT' Rutgers University, Bureau of Economic Research, New Brunswick, N. J.,' June 1975.

B. *Costs*

The major costs of the vocational rehabilitation program are case service costs, which are usually variable, and overhead costs, which are primarily fixed. Typical rehabilitation costs might include those for administration, counseling, placement, medical services, diagnosis, physical and mental restoration, training, facilities usage, services provided by other agencies, etc.

One other large cost of the program is the opportunity cost of wages lost by clients while they were in the program. For instance, if a client could have earned twenty-five dollars a week but entered the rehabilitation program instead, a cost to society would be twenty-five dollars of output foregone for each week the client was in the program and unable to work.

Federal-State Vocational Rehabilitation Program as a Social Investment

Most benefit-cost ratios computed for the rehabilitation program indicate that the program is returning more to society in productivity gains than the costs expended. Some of the more conservative estimates of the ratio of benefits to costs are 5 to 1. Other estimates have run as high as 70 to 1. Our own research favors the conservative estimate.

Benefit-cost analysis is only as good as the data available and the assumptions we must make. The ratio should not be seen as a single criterion for social investment, but as a useful tool for decision-making. If we realize that the rehabilitation program returns five dollars for every one dollar we devote to it, we can state that although there may be more productive investments, the rehabilitation program is a good one.

POTENTIAL LEGISLATION AND IMPACT ON HANDICAPPED PERSONS

The current structure of programs for handicapped individuals could be radically changed with the passage of legislation. National health insurance, negative income tax, a nation-wide temporary disability insurance, or the introduction of national "no fault" insurance are among potential changes which would have immediate consequences for the handicapped.

It is foolish to make blanket predictions about the effects of these programs on handicapped individuals. Although we can speculate that there is a strong possibility that national health insurance will be introduced in the next decade, we are uncertain which of many proposed national health insurance plans will be adopted by the Congress. Similarly, the importance of a negative income tax and its impact on the disabled would depend, among other things, upon the minimum level of income support, the effective tax rate and breakeven point of the tax adopted.

We shall consider potential legislative changes by examining those areas where these changes would probably have their greatest impact. Given that we do not know the specifics of the legislation to be adopted, we shall outline impacts in general terms only.

National Health Insurance

The introduction of a national health insurance program could radically alter the current structure of medical programs, but it would also have an influence on the level and distribution of transfer payments. Poverty and disability are linked. The causality may be two-way, i.e. poverty can cause disability through the lack of ability to purchase medical care—preventative or curative, and disability can cause poverty by depleting a family's assets and by depriving a wage earner of the ability to earn a livelihood. If the early treatment of diseases, illnesses or injuries can diminish the prevalence and severity of disability, the demands placed upon certain income support programs should be diminished. To this extent, at least, national health insurance will influence transfer programs.

Certain medical programs could be expected to disappear completely with the introduction of some of the proposed national health insurance plans. Medicaid, for example, would be eliminated if the Long-Ribicoff plan were adopted.* Other national health insurance schemes might involve revision of Medicare and related programs. The disabled would not necessarily gain with the passage of certain national health insurance bills,* and each proposal must

*See Karen Davis, *National Health Insurance: Benefits, Costs, and Consequences*, The Brookings Institution, Washington, D. C., 1975, p. 85.

**Ibid.*, pp. 94-96.

be examined to determine what the benefits and costs are to the disabled. The benefits and costs need not be the same for the disabled and nondisabled populations. Major considerations should be who is covered by the various plans, what services are provided, are the plans publicly or privately financed, what are the incidences of the tax burden and the distribution of the benefits.

National health insurance would obviously affect the medical vocational rehabilitation program; it could change or eliminate the necessity of providing some medical services through veterans' hospitals for service or non-service connected disabilities; and it could replace some medical payments made under temporary disability insurance plans, workers' compensation schemes, and the general assistance program. There are other programs which would be directly affected by national health insurance but we need not catalogue them here.

It is interesting to note that national health insurance has the *potential* to provide uniform services across states and people. Two disabled people with needs for medical treatment could both receive services under national health insurance without recourse to status or predisability position. A veteran and non-veteran, for example, could both be treated similarly under the plan. We may or may not consider this to be desirable. For example, we may value medical treatment more highly for those who were injured while working. If national health insurance is adopted which provides for universal coverage and extensive services, we shall be stating that we do not value the basic treatment of one group more than another. The extent of services and their intensity will tell us if we value the treatment of the disabled more than the non-disabled.

We have not addressed the question of the balance of medical services for the disabled which are provided through the private market. The way in which the program is financed can alter this balance, change the insurance industry, and directly affect medical care costs.* The disabled, and all citizens, will be the beneficiaries and cost-bearers with the distribution of the benefits and costs depending on the specific nature of the chosen plan.

*This would include rates of price increase in the medical care sector.

Negative Income Tax

A negative income tax would have its strongest direct effect on those programs with an income support rationale. The tax would provide positive income transfers to those with incomes below a specified level. In effect, the program would establish a minimum level of income that would be guaranteed to everyone. Those with incomes above the guaranteed minimum would receive positive transfers, but at a reduced rate, until some breakeven point of income is reached. All incomes above the breakeven point would receive negative transfers, i.e. they would pay positive taxes.

Among the current programs that aid the handicapped are several which provide income support. These include Supplemental Security Income, Aid to Families With Dependent Children and Veterans' Compensation for Non-Service Connected Disability. Income support programs for the disabled currently provide income transfers to those who meet a means test, as well as satisfying other eligibility criteria, sometimes specifically requiring that the person meet a given definition of disability. A negative income tax plan would serve a similar purpose and would probably eliminate most current income support programs. The tax would continue to serve as a back-up for the income maintenance system and for private insurance. It would assist those who were ineligible for income maintenance (or whose income maintenance payment failed to keep the individual above the cut-off point) because of age, family status, lack of labor market experience, failure or inability to purchase private insurance, or some other reason.

A negative income tax would probably be financed out of general revenues, thereby partially sharing the cost burden of a handicap at least for those handicapped people in poverty.* Using general revenues would mean that the burden of the program would be progressive. Some income maintenance programs, on the other hand, are financed with a payroll tax. These are regressive with respect to collections although as the maximum income below which they are collected rises, the regressivity falls. In addition, the net benefits of income maintenance programs for the disabled may be positive.

*A more direct means of sharing the cost burden of a handicap, no-fault insurance, is discussed below

A negative income tax could be designed so as to provide uniform payments to all recipients, a fact often touted as one of its strong points. If we consider that the levels of payments under workers' compensation, an income maintenance program, vary dramatically across states, we may find the uniformity of the negative income tax attractive. However, we should be alive to the fact that a negative income tax would serve all people. It may well be that the disabled have differential income needs generated by their handicaps. For instance, a handicapped citizen may require special equipment, such as a wheelchair.* Therefore in deciding on what base the amount of the transfer is to be calculated these differential needs must be considered.

Ideally, a negative income tax would diminish the resources expended in disability determination. This would not eradicate the necessity for disability determination, however, as the discussion on the differential needs of the handicapped makes obvious.

Income maintenance programs are generally related to an individual's capacity to work. They are designed to replace lost income, or the capacity to earn income. These programs need not disappear with the advent of a negative income tax. We may wish to retain the distinction that people be reimbursed according to status (veterans) or job situation. If the levels of payments under a negative income tax plan were set high enough, most income maintenance programs *could* also be eliminated. We must realize, however, that the design of the tax might have incentive or disincentive effects with respect to return to the labor market. It would also alter the structure of private insurance markets.

The choice of a particular minimum level of income will have several effects on the pattern of insurance protection. For example, those individuals, who in a non-negative income tax state would have purchased private insurance, will now be discouraged from doing so. Also those who would have taken the risk of a disability occurring and chosen not to purchase private protection will, in effect, be forced to purchase such protection through the public plan. Another result would be that those who would have been unable to purchase insurance because of their low income level will now be covered against the risk of disability. If this last result is deemed important and the other effects are judged undesirable, a possible alternative would be direct government subsidization of the purchase of disability insurance by the poor.*

If minimum levels were set high enough to eliminate certain of the income maintenance programs such as veterans' disability payments, we could, in effect, be placing ourselves in a position where we are changing the social contract. Consider a citizen who makes choices about the allocation of time. The citizen decides to enter the military service rather than take employment in the private market. Part of the allocation decision could resolve around the benefits the military offers. The citizen may have decided that his preference would best be expressed by lower money income now, but with insurance against disability and with a guaranteed retirement income in the future. Although these benefits may still accrue, the choice has been superceded.

The negative income tax concept has much to recommend. Depending upon how high the minimum income level is set, what the effective tax rate and breakeven point are, it could be a great aid to the handicapped. It will be necessary to consider the differential needs of the handicapped. It could eliminate current income support programs, and influence the private insurance market.† It will not be an income cure-all and, finally, it will raise equity questions concerning risk.

Nationwide Temporary Disability Insurance and No-Fault Insurance

Two other programs which could be introduced are a nationwide temporary disability insurance plan, and national no-fault insurance. Currently six jurisdictions have compulsory temporary disability insurance. This social insurance program covers short-term disability caused by non-occupational illness or injury. Lawrence D. Haber has poinated out that forty percent of "wage and salary workers in private industry have no private or government protection against loss of wages from non-occupational

*We are considering a negative income tax without a concomitant national health insurance plan here.

*It should be noted that this last alternative requires careful design to avoid unintended results in related areas.

†Although we have not made the point explicit, it would also effect the medical programs.

illness or injury."* Compulsory temporary disability insurance in all jurisdictions would insure against income loss for many of these people. However, this income maintenance proposal does not provide for those citizens who are not attached to the labor market. We may not want it to. In addition, temporary disability insurance would probably be financed with a payroll tax with the implications we discussed in the negative income tax section, i.e. it would be regressive.

Temporary disability insurance could also provide for medical care payments. The income transfer and medical aspects of temporary disability insurance would both probably reduce the burden on some longer term income maintenance programs. This is based on the assumption, as made above, that early intervention decreases the prevalence and lessens the intensity of disability.

Some states have introduced "no-fault" automobile accident insurance. These generally provide for medical payments without regard to personal liability. The basic concept could be extended to provide for medical payments and income loss, real or potential, for any accident regardless of its nature. New Zealand has recently enacted such legislation.

Under New Zealand law everyone under the age of 65 is compensated for an accident. Accidents of wage earners are compensated from employer contributions and the contributions of the self-employed. Motor vehicle accidents are compensated from a separate motor vehicle fund for those non-wage earners involved in automobile accidents or wage earners involved in automobile accidents which do not "arise out of and in the course of employment."† Those non-wage earners who are injured in accidents other than automotive are compensated from general revenues.

If a no-fault plan along the lines of New Zealand's were adopted, the workers' compensation programs would probably be eliminated, current no-fault accident plans would be consolidated and unified, and those public assistance programs providing payment for medical treatment for non-wage earning accident victims would be eliminated.

A no-fault plan should save on administrative costs. It could retain safety incentives if collection rates were structured to reward safe employers and drivers. It would take much of the uncertainty out of the current system where payment is probabilistic.

The implications of each of the alternatives we have discussed are based on varying amounts of information and conjecture. For this reason the Conference participants may want to focus on individual program changes as well as developing proposals for several new, less comprehensive, programs rather than the major changes discussed in this chapter. If such an approach is taken it will be wise to carefully trace all the impacts of the changes including the effects on the distribution of costs and benefits of existing programs and on the post-program situation of all the handicapped. Perverse results from attempts to fine-tune the structure of support for the handicapped have been known to occur and we should be alert to such possibilities. Thus an overview of the programs is necessary as is serious consideration of the possible methods designed to consolidate support and improve the well-being of the handicapped.

ECONOMIC ISSUES FOR CONFERENCE REVIEW

The Costs of Handicaps

There is no denying the fact that a substantial proportion of the population is disadvantaged as the result of limitations imposed by physical or mental impairments. The economic aspects of the situation faced by these individuals have been addressed throughout this paper. Now we bring together many of the thoughts and implications introduced above and begin to address ourselves to the task of developing a sharp focus for conference debate on the economic concerns of handicapped individuals.

It is evident that the problems created for handicapped individuals are numerous, complex and often distinct from the problems facing other disadvantaged groups. These difficulties cover the gamut from simple income needs to mobility assistance, to architectural barriers, to medical and other rehabilitation services. We have stressed the importance of thinking of these matters in terms of cost. Clearly, handicapped individuals are burdened with costs

*Lawrence D. Haber, "Sickness and Injury Cash Benefits: A Proposal for Program Planning and Integration," Office of Research and Statistics, Social Security Administration, HEW, p. 361-376.

†A summary of the Act can be found in D. R. Harris, "Accident Compensation in New Zealand: A Comprehensive Insurance System," *The Modern Law Review*, Vol. 37, No. 4, July, 1974, pp. 361-376.

beyond those normally associated with the non-handicapped population. In part, these costs define the boundaries of the problem. When the costs of an impairment are high and cannot be shifted to others, the impact of the impairment is likely to be large and hence a severe disadvantage. When many of the costs can be offset through various mechanisms, including effective public programs, the problems associated with handicapped individuals are lessened.

We should note that the concept of costs we use is broader than most would expect. Thus the costs of a handicap include not only the direct expenditures to overcome the immediate consequences of the condition but also the lost income, the value of the ability to perform tasks the person is now incapable of doing, the value of opportunities or choices that must be foregone, and the psychic costs of pain, suffering, loss of self-image and independence and so on. Each of these costs lowers the level of well-being or utility for the individual. Only when we can fully eliminate or compensate for these costs (which in some cases is clearly impossible) can we put the person in a status equivalent to the pre-handicap situation.

Thinking of handicaps in terms of the associated costs and viewing these costs as the basis for a reduction in well-being allows us to analyze the problems in a rather straightforward manner. If costs are used as a guage to measure the severity of the condition, we would have a better guide to allocating resources to handicapped individuals in an optimal manner, given social preferences for helping the severely and less severely handicapped people. For example, it may be decided not to use limited resources to assist those handicapped suffering minor costs while aiding those individuals who face a significant cost burden due to their impairment.

The decisions society makes as to how much of these costs are to be met and by what methods are critical to the situation of handicapped individuals. One major goal of the Conference is to increase awareness about the costs of being handicapped. While we have little to say on how such a goal might best be achieved, there are obvious advantages to informing the public of the magnitude of the costs. A greater awareness of the costs is likely to result in a public willingness to take a greater portion of the cost burden off handicapped individuals.

Sharing the Costs

Two reasons for an increased willingness on the part of society to share the costs with handicapped individuals are apparent. First there is no doubt a strong argument to be made over the unfairness of placing the burden on handicapped individuals alone. Since many of the causes of handicapping conditions are largely random, it would appear inequitable to force the handicapped segment of the population to bear all the costs. Much of private philanthropy on behalf of handicapped individuals is the result of public recognition of the random way handicaps may strike. Additionally, public willingness to be taxed for transfer programs, such as SSI, indicates a similar equity judgment. If the general public could be made aware of the significant magnitude of these costs and the possibility of eliminating many of the costs through means other than direct cash transfers, there would undoubtedly be an increase in the willingness to contribute to programs to aid the handicapped.*

Along with the equity argument made above, it is possible for us to think of the rest of society establishing mechanisms to assist the handicapped for reasons more closely aligned with their own self-interest. Under the right circumstances, there may be efficiency gains to be derived by achieving a specified level of public protection for the costs of handicaps. If the nonhandicapped recognized the possibility that a handicap may befall them or someone in their family, established programs can then be viewed as an insurance device. Rather than having to bear the costs of the handicap themselves, people aware of public programs understand that their cost burden will be shared with the rest of society.

The availability of this option to share the costs of a handicap suggests the non-handicapped receive benefits of a sort from possessing the knowledge that public programs and support will be at their disposal should they become handicapped. The existence of these benefits implies that members of society will be willing to help maintain public programs for handicapped individuals.† This willingness combines

*The success of telethons that clearly show the costs of various handicaps may be more than partially explained with similar logic.

†We note that these benefits exist whether or not the person ever has to make use of the program. Having the option is what generates benefits.

with income levels, tastes for risk bearing, perceived chances of becoming handicapped and the associated costs, available alternatives in the private sector and other factors to determine what is in effect a demand for programs for the handicapped.* We referred to this demand as an efficiency consideration because the focus is on individuals seeking to improve their own well-being. This fact should be recognized because it is of significance as one begins to search for ways to generate public support for handicapped individuals and related programs.

We have posed two arguments, one equity based, the other a result of efficiency considerations, that might validly explain society's willingness to share the costs of handicaps with handicapped individuals. We are not able to provide empirical evidence that will show how each argument is responsible for certain programs and amounts of assistance. There may be other more important reasons for having society share the burden. We believe the two discussed are among the more prominent.

If our judgment is correct, there exists substantial room to debate and decide upon the best strategy to increase public willingness to share the cost burden of handicapped individuals. If the Conference participants decide that the public is not fully aware of the costs of handicaps and of their own chances for incurring these costs, there is obviously an opportunity to improve the quality of information and the level of public knowledge concerning the handicap.† The issue for debate then becomes one of determining the most efficient way to use resources to extend society's knowledge of the problem. How can the Conference successfully transmit the true nature and magnitude of the costs of a handicap and what it means to bear the brunt of these costs?‡

In debating the issue the participants will do well to retain the basic equity and efficiency arguments that we suggested form the basis of the public's willingness to assist the handicapped. Thus efforts must be directed at stressing the randomness inherent in the onset of a handicap. The magnitude of the costs, the available solutions, and the possibility of this large cost burden being placed at some time on the non-handicapped are all important facts the public needs to have to reach correct decisions on programs for handicapped individuals. Of course, even with complete information, there is no assurance that what the non-handicapped public is willing to supply will meet the desires of the handicapped. If this is the case, changes of a more fundamental nature in individual judgments about fairness, risk-bearing and so on may be required. The long-run alteration of such basic opinions and preferences while certainly of less immediate concern to those presently handicapped may also be matters deserving the attention of Conference participants.

Expenditures and Choices

At the same time measures are undertaken with an eye toward increasing public support for handicapped individuals, there remains the issue of how best to spend money already allocated. We have reviewed the specific means whereby judgments can be made regarding how successful current programs are in achieving their stated ends. Even should additional funds be forthcoming, there remains the necessity of making decisions as to the most appropriate uses of that money. Given that one of the goals of the Conference is to develop recommendations for actions designed to improve the status of handicapped individuals, it becomes evident that we must understand how the possible uses of the money are likely to contribute to attainment of the desired ends.

One can easily interpret the Conference mission statement to imply that program expenditures should be designed to achieve maximum independence, dignity and integration into com-

*This demand is associated with the nonhandicapped. The demands of the handicapped are treated separately below.

† We note that at some point it will become too expensive to increase public information on this subject. When the benefits to society of the extra information generated by an added dollar of expenditure designed to improve information are less than the added dollar, it is clear society could be better off spending that dollar elsewhere or not at all.

‡Another possibility is that we may be at a point where both the equity and efficiency bases for public support are fully perceived and all relevant information has already been disseminated. If this is true, that is if the public fully understands the true costs of the handicapped and the value of the possible benefits they (as the non-handicapped) may receive if handicapped, then we may in a situation where no more in terms of public support can be expected. There is also the possibility that although the public is aware of the equity and efficiency issues that were raised, they have been unable to have their preferences for support of the handicapped correctly interpreted in the political arena. If this is the case, a different solution is called for. How public preferences are translated into policy in our system of government, while outside the purview of this paper, may be a matter of substantial concern if the situation described in this footnote exists.

munity life for handicapped individuals. In large part, because of the nature of these goals, it is impossible to reach a firm judgment on what individual programs add to these objectives. In part some of the confusion can be reduced by returning to the notion of disability we discussed earlier. Perhaps it might be more appropriate to infer how well programs reduce disability or the inability to function in social roles. Thus a program that results in more people having no mobility limitation or in successful rehabilitation (in terms of work) would be highly valued. Programs whose benefits are nebulous and can be expressed only in general terms will require closer examination to see if there is truly a reduction in disability.

We leave for the moment the difficulty in establishing measurable and valid goals, there remains a more fundamental problem. Given the basic constraint on resources how are we to decide which goals and which individuals are to receive priority? Certainly there is no argument that the world would be a finer place if no one suffered as a result of a physical or mental handicap. Yet it is simply not possible to reach such a point. Choices are the basic characteristics of any economy. These choices must be made. The final outcome will depend on the values or weights people place on the goals as well as our ability to achieve, and the cost of achieving, those goals.

It is useful to think of the situation in the following terms. Given some specific, measurable objective, a set amount of available resources, certain information about how effectively these resources can be utilized and information on the characteristics of those to be served, what is the best way to spend these resources? Although all disability could perhaps be eliminated (assuming the necessary knowledge and technology were available), achieving such a goal may simply be too costly. It is important to recognize that "too costly" refers to something larger than dollar expenditures. We mean the term to imply, too costly in the sense of other opportunities that must be foregone because the limited resources were diverted to other uses. For example, increasing expenditures for handicapped children may mean less dollars spent on non-handicapped children.* Obviously, important decisions must be made as to how much of the resources should be transferred and from the education of which children. The transfer of funds suggest we value what the given amount of resources can do for handicapped children more than what these resources could do in their prior use.

It may be easy to reach a large majority on some of these judgments. For example most might agree that an extra expenditure for soiid oak desks to replace perfectly well-functioning desks made of some synthetic material could be better utilized to provide special services to see that the handicapped children are able to get to school. But often the choices are less clear and subject to considerable controversy. Thus, should money be taken from a school for non-handicapped children and used to buy better books for the handicapped children if the change will mean a shift in the teacher-student ratio from 1:20 to 1:30 for the non-handicapped children?

A large amount of technical information regarding what these input changes would do to output as well as information with respect to how important are the different outputs is needed before any decision can be reached. Clearly, though, decisions of this sort are made all the time with something less than complete information. The Vocational Rehabilitation Act required a shift in resources toward the more severely disabled. A new education bill requires more money be spent on the education of handicapped childred. Our purpose in pursuing the entire previous discussion is to stress the fact that resources have other uses, that choices must be made and that policy cannot be made in a vacuum where the preferences of only one group are considered. A fuller understanding of these principles will lead to better formulated suggestions for change. Perhaps these suggestions should include ways to alter preferences or the values placed on the ends generated by the competing demands for the resources. Also information concerning the likelihood of achieving outcomes of a specific nature will carry greater weight when the proposed use of funds goes up against an argument for a rival use of the same funds.

As we begin to examine the possible uses of a given amount of funds, it is important to retain the distinction between direct and indirect programs. The former can be viewed as those

*Certainly and resources must come from some other use, suggesting we are deciding which use is more valuable.

programs providing income and services to individuals. Examples include DI, SSI, and VR where the assistance, whether in-kind or in cash, goes directly to the individuals in question. Indirect support comes through programs whose basic design is social and which affect the environment in which the handicapped function. One of the more significant forms of indirect support is changes in the legal system, including legislation and litigation defining the rights of handicapped individuals. Other aspects of society that will have an impact on the handicapped are the general situation of the economy and the research on ways and means to aid handicapped individuals.

Turning first to direct support, several specific issues deserve debate. The bases for distributing income transfers at present include the person's prior status and current income level. The Conference participants must be concerned with determining whether or not the allocation of resources that results from the current structure is appropriate. To make this judgment, it is apparent that substantial information is required. We must be knowledgeable about the ability of the person to work, the insurance protection the person has secured for himself, either through public or private means, the added cost burden associated with handicapped individuals and many other factors that will determine the situation for handicapped individuals.

In addition to these objective pieces of information, we must consider society's values and preferences, including the opinions of handicapped individuals. Thus we must decide how a disabled person, who is unable to work will be supported by society. Currently, the eligibility requirements for the programs establish who will receive varying amounts and kinds of assistance. These conditions must be reevaluated and judged on current standards. Questions include: (1) should predisability status or source of disabling condition be important in determining the amount and kind of support; (2) what is an adequate standard of living for persons with handicaps of varying degrees of severity; (3) how should society share the costs of the handicap?

A number of factors must be considered as one attempts to answer each of these questions. For the first question the existence of separate support systems for disabled veterans, workers (depending on whether or not they are injured on the job), miners, government employees, relatives and survivors of workers and veterans cannot be overlooked. The status of the disabled poor not sufficiently covered in other programs and the ability of disabled individuals to benefit from specific kinds of services must also be addressed in choosing among alternative uses of funds. The current system, implicitly or explicitly, answers, or at least resolves, each of these issues. We believe the outcome of the Conference can be a significant step toward developing general guidelines that will serve to clarify the choices regarding programs and their structure. Special income needs should be verified, the importance of cause of disability and predisability status in program support should be debated, the basis for establishing the severity of the condition and thus perhaps level of support and services must be arged and finally the interaction of support and services accorded the disabled and non-disabled must be based on some rational decision-making.

Indirect support, by its very nature, requires less of a body of information on the situation of the handicapped individual and more on the overall functioning of handicapped individuals in relation to society. The main focus here is to establish a structure of programs and rules to provide an environment in which handicapped individuals can function to their highest capacity. Still there must be retained a recognition of the constraints on developing such a set of programs and rules. Resources for programs are limited, technology and information are not complete and costly to obtain and the Constitution sets basic rules which govern changes and limit options.

Three of the indirect factors that affect handicapped individuals are the establishment and enforcement of laws, the health of the economy, and the knowledge, generated by research, that exists regarding our ability to lessen or eliminate the burden imposed by the handicapping condition or to prevent the condition in the first place.

We have stressed the implications for handicapped individuals of societal preferences and values. Much of these matters are worked out through the establishment of laws. Many of the kinds of support accorded handicapped individuals are the direct results of legal acts or judicial rulings. Federal and state legislators set expenditure levels and program requirements. Clearly the status of handicapped individuals is affected by these rulings and laws. While we could go

into great detail on economic aspects of the law, we shall leave these matters to another forum.

Let it suffice at this point to note that the impact on the status of handicapped individuals of new interpretations of existing laws or new laws can be great. In many cases these may be the most appropriate means to achieve desired ends. As we will argue later on, the private sector often fails to work satisfactorily and the use of the legal system may be the most efficient means to achieving a desired end, whether it be services accorded handicapped individuals, the attainment of a satisfactory distribution of income or some other goals.

The health of the economy can undoubtedly explain much variation in the situation of handicapped individuals. On one side, it is evident that an expanding growing economy will mean more resources for all. Thus the programs for handicapped individuals are more likely to grow and increase in both coverage and level of support during expansionary rather than recessionary times. On the other side, handicapped individuals will find improvement along with the economy in the same way as other groups whose labor force participation is affected by the need for their services. Whether true or not, employers often perceive extra costs or lower productivity associated with hiring handicapped individuals. But as the demand for a product grows, the employer will turn to new workers to expand production. Thus a growing economy can counteract employer reluctance to hire handicapped individuals.

The reverse findings hold, when the economy weakens. Employment of handicapped individuals may be discouraged because of a lessened demand, and hence a lowered willingness to pay a certain price for a certain quantity of goods. Another aspect of macro-economic aggregates often classed with those factors having a negative influence on handicapped individuals is inflation. Rising prices worsen the situation of anyone whose income does not grow as fast as the prices of the goods they buy.

To some degree the consequences of inflation for many handicapped individuals are minimized by cost-of-living adjustments in transfer programs and the growth of public expenditures in other programs. Trends over the recent years show expenditures in these areas more than keeping pace with inflation. An additional factor to keep in mind is the distinction between the bundle of goods on which inflation is calculated and the bundle of goods purchased by handicapped individuals. For example if handicapped individuals use very little public transportation and it is public transportation that is responsible for much of the growth in the price index, then the reported figure will overstate the influence of inflation on handicapped individuals. Similarly, the reverse may happen and reported figures will understate the influence of inflation. An additional factor to recognize is that if the component of the price index which is rising is needed by handicapped individuals but is largely subsidized for them by the government (two examples could be medical care and food) the impact of inflation is further lessened.

In sum and in recognition of the need for empirical verification for many of our prior conjectures, it would appear that Conference participants should discuss the ways and means to influence a growing economy with the aim of producing more resources and employment opportunities for handicapped individuals. Frank recognition of the possible side effects such as a rise in prices should be faced, although the impact of inflation has been lessened due to continued subsidization of necessities and continued application of cost of living adjustments to transfers and other support for handicapped individuals.

We believe that in the long run this kind of resort to utilizing market incentives as the means to encourage the private sector to increase demands for the disabled, with the public sector there to meet the needs of those unable to work, are likely to be most effective. Attempts through legislation to alter employer demands for handicapped individuals will not nearly be as powerful as the forces that will come into play in a growing free-market-economy. It is the incentives provided by the private market that will be more valuable in the long run.

The other side of these arguments deserve mention to that useful debate can arise. Some argue the valid point that dependence on the private market means the fortunes of handicapped individuals will fall and rise on no account of their own. Of course the changing nature of the overall labor market situation undoubtedly lends validity to this argument. But of what significance is it? Many others move in and out of the working population or to different jobs as the basic economic structure is altered.

portation for all handicapped individuals because that is the fair solution will not be enough to achieve the desired end. Again, as before, we believe the long run solution is through the market and there, preferably by using those policies that produce the desired result with little interference in the workings of the market. Yet, if the need is critical and time is of utmost importance, direct public action may be more desirable. In such cases, the costs of enforcing sanctions and requiring inefficient production must be carefully weighed against the benefits accruing to all of society as a result of achieving an equitable solution.

Another important source of indirect support for handicapped individuals is the information generated by research. Successful well-done research can provide new detail as to how to retrain handicapped individuals or it can tell us useful things about the characteristics of handicapped individuals. Earlier we stressed the significance of the costs of handicaps. Research can inform us as to the nature of these costs and who is bearing them. Such research provides the basis for programs aimed at reducing the cost burden on handicapped individuals. Program evaluation is an important requirement in the design of a system that creates incentives for handicapped individuals to strive for dignity and independence.

A product of this Conference could very well be a research agenda directed at answering specific questions about the costs of handicaps and how impairments cause disabilities, particularly how social factors interact with individual characteristics to determine whether or not an impaired person becomes disabled. Another area where information would be useful is the incentive structure needed to achieve satisfactory employer behavior both with regard to safety precautions, insurance plans and hiring policies. In a larger sense when there is competition for resources it will likely be those areas where needs are firmly established and the effectiveness of available ways to deal with the problems that will be the beneficiaries of added support. Tighter budgets and more sophisticated analytically-oriented office holders will require careful and thorough evaluation of all alternatives before decisions are made.

Summary and Conclusion

We have argued for serious consideration of a number of economic questions that concern handicapped individuals. Our presentation has been broader than the non-economist would have expected. Yet the study of the allocation of scarce resources among competing ends is an effort limited simply to matters of expenditure and income levels.

Several issues of direct concern deserve to be reiterated. A basic issue is how handicapped individuals are to be defined and whether classification based on cost burden, medical measurement or some other means is most valuable. A second problem area is the structure of support for handicapped individuals. How should the public role be altered, how is differential treatment to be determined and how can effective incentives in the private market be structured to achieve the desired ends? One of the most significant matters that must be dealt with is the treatment of handicapped individuals vis-a-vis other disadvantaged groups. The situation arising out of consideration of a negative income tax and national health insurance raises serious questions in this regard.

Of major importance in all the discussion is that we retain the focus on the general goals we seek to achieve, the fact that alternative methods to arrive at the desired ends are available, and that each option has a cost. If we view the physical or mental condition as constructing obstacles and reducing options to those so affected, then policy choices have a rather direct basis for comparison. For example, does an increase in transfers to handicapped individuals improve the chances of attaining dignity and independence more or less than if the same amount were to enforce a legislative edict?

Along with judging the efficiency with which money is spent we must evaluate the distribution of these resources. Should the severely handicapped individuals receive priority in transfers and the less severely handicapped preference for services? Should the aged and children receive greater per capita support than those in the working age group?

The participants at this Conference must come to grips directly and not implicitly, as has often been the case in the past, with these kinds of questions. Legislation and legal rulings have specified strict funding and staffing rules for (sometimes) well-defined classes of people. Handicapped individuals deserve a voice in establishing these rules. But it must be a reasoned voice and to be effective, a voice based on an understanding that limited resources require

With sufficient support during periods of slow or no growth the position of handicapped individuals need not become disastrous. The system of transfers and training provide a back-up to the labor market. A major choice may be between increasing transfers or training or perhaps using the funds to provide wage subsidies for the employers who hire handicapped individuals.* A wage subsidy will lower the cost of hiring handicapped persons and hence make such an option more palatable to the employer. An economic approach of this sort will prove a better tool to expanding employment of handicapped individuals than much of the moral suasion of less-than-fully-enforced legal rules. An experiment with varying levels of subsidy could generate valuable information for future policy choices.

The economy we have been discussing in terms of employment is largely a private one. Our presentation up to now has been directed toward the factor market. The other side of the traditional circular flow is the product market where goods and services are demanded and supplied. The market rations resources to the production of those items where demand is sufficiently high to make production worthwhile. Given an equitable distribution of income at the beginning, the perfectly operating market will produce exactly what society desires, as expressed by the willingness to pay a specific price for a certain level of output. As price and quantity vary we get a locus of points we refer to as a demand curve. It is in response to this demand curve that the private sector will produce goods.

For a number of reasons the private market may fail and there thus arises a need for public intervention. Public action can vary between provision of a good to direct production of the good to subsidies or penalties to encourage optimal private-market behavior. As we turn to the demands of handicapped individuals, it is useful to see why certain goods valuable to handicapped individuals go unproduced. Why are wheelchairs produced and seeing-eye-dogs trained? Why are specially adapted buses and buildings so difficult to have built?

*A review of the basics of wage subsidies can be found in Barth, Carcagno and Palmer, *Toward An Effective Income Support System: Problems, Prospects, and Choices*, University Wisconsin, 1974.

Private markets operate in response to demands.* Because there are not a relatively large number of people with large incomes demanding special goods and services for handicapped individuals, the quantity demanded and the price they are capable and willing to pay is too low to make production worthwhile. If we could find a way to increase demand or lower the costs of production, we could move to a situation where supply might equal demand.

There are many other means at hand to adjust the market outcome. These will be mentioned below and Conference participants should consider both the costs and benefits associated with each argument. Only when the true and full implications of each alternative are recognized can we expect the appropriate social policy to be chosen.

One option to alter demand is to give handicapped individuals more income with which to demand the goods they desire. A second possibility is to find ways, through research, to produce the goods in question at lower cost. For example, some way to alter housing or transportation so that it will be accessible at a reasonable price would be a significant improvement. Similarly, a government subsidy, should the private sector be moving too slowly, could encourage research and production along these lines. Legal action could require the supply of certain goods to be set at acceptable levels. Government could produce the good in question itself as in many of the programs for veterans.

There are numerous difficulties in assessing each of these alternatives. For now let us acknowledge the significance of equity considerations by noting that such judgments could outweigh the costs of many proposals. The participants, though, must recognize that it is a social equity judgment and not their own. Thus

*Demands are, as we noted above, a representation of willingness to pay. The significant factors affecting willingness to pay are price, income and tastes. It is generally true that lower prices result in more goods being sold. Also higher income suggests a greater willingness to pay. Tastes are based on how important a good is to someone. As it becomes more important or close to "a necessity," we would expect a greater willingness to pay. The reverse holds for luxury items. All three factors interact with one another to determine an individual's demand which in turn is a part of the overall market demand.

Supply is largely determined by the costs of production. A producer will be willing to supply varying amounts of the good as his costs vary. Thus it is generally true that increases in supply bring increased costs which means firms will require a higher price if they are to produce and sell their goods.

simply arguing for adequate housing and transchoices and that each option has numerous cost and equity implications. Each option must be considered in relation to general goals and the most appropriate choices must be defended effectively and with vigor by all concerned citizens.

ACKNOWLEDGMENT

The White House Conference on Handicapped Individuals wishes to thank the following individuals who have contributed significantly to this document:

Monroe Berkowitz, Ph.D.,
Professor of Economics and Director, Disability
and Health Economics Research Section,
Rutgers University

Jeffrey Rubin, Ph.D.,
Assistant Professor, Department of Economics,
Rutgers University

John S. Worral, Ph.D.,
Assistant Director, Disability
and Health Economics Research Section,
Rutgers University

FULL EDUCATIONAL OPPORTUNITIES FOR HANDICAPPED INDIVIDUALS

Awareness Paper Prepared by

The Council for Exceptional Children
Reston, Virginia

TABLE OF CONTENTS

	Page
Introduction	249
The Legal Right to Education	251
Financing of Education for the Handicapped	252
Delivery Systems	254
Early Childhood Education	256
Educational Problems of the Severely Handicapped	260
Career Education	263
Continuing Education	266
Personnel Requirements for Education of the Handicapped	268
Research and Education for the Handicapped	270
Public Information and Education	272
Summary	274
References	275
Additional Readings	278
Appendix A: The Education for All Handicapped Children Act, Public Law 94-142	278
Appendix B: Methods of State Fiscal Support	284

INTRODUCTION

Education is the right of all. This principle is based on the philosophical premise of democracy, that every person is valuable in his or her own right and that each individual should be given equal opportunity to develop full potential. Too often this premise has not been applied to *all* persons. Throughout the history of American education, individuals with special learning needs have faced the policy of closed door exclusion rather than inclusion.

Who are the children schools have tended to neglect or exclude? Who are the youth or adults who have sought relevant training only to face indifference and apathy? They are the individuals who have been called "handicapped" and who because of physical, mental, emotional, or learning problems require specialized education services. In the United States there are an estimated 7 million school age (plus 1 million of preschool age) deaf, blind, mentally retarded, speech impaired, motor impaired, emotionally disturbed, multiply handicapped, learning disabled, or other health impaired children. There are many times that number of handicapped adults.

Handicapped children and handicapped adults require different kinds of education programs and services. Although this paper identifies various special education needs, the emphasis is on those for the early years and the school age child. It is during this time that an appropriate, relevant education can provide the foundation for a successful, rewarding life.

Although handicapped children represent approximately 10% to 12% of the school age population, although the number of handicapped children receiving special education services has grown, only about 40% of these children are receiving an education designed to enable them to achieve to their maximum capacity. Additionally, there are an estimated 1 million handicapped children who are totally denied access to a free public education. Further, there are an estimated 125,000 mentally retarded, emotionally disturbed, and physcially handicapped children who live in state institutions where education programs are inferior or nonexistent (Weintraub, Abeson, & Braddock, 1975).

On November 29, 1975, President Ford signed the "Education for All Handicapped Children Act," which is now Public Law 94-142. (See appendix A for a detailed discussion of the law.) This landmark legislation represents a major breakthrough in insuring the appropriate education for all, particularly those children and youth who were unserved or underserved. Public Law 94-142 is a federal/state partnership with the federal government firmly committed to financial support. Education programs, however, remain the responsibility of the state governments and local school systems.

Public Law 94-142 makes a number of critical stipulations which must be adhered to by both states and local school systems. These requirements including:

- Assurance of extensive child identification procedures.
- Assurance of "full service" goal and detailed timetable.
- A guarantee of complete due process procedure.
- Assurance of regular parent or guardian consultation.
- Maintenance of programs and procedures for comprehensive personnel development including inservice training.
- Assurance of special education being provided to all handicapped children in the "least restrictive" environment.
- Assurance of nondiscriminatory testing and evaluation.

This current awareness paper was prepared by The Council for Exceptional Children (CEC), Reston, Virginia, for the White House Conference on Handicapped Individuals. However, it should be noted that this paper has not been adopted as an official position document of The Council. Contributors to this paper were: K. Eileen Allen, University of Kansas; Gloria Calovini, Illinois State Department of Education; William C. Geer, CEC, Norris G. Haring, University of Washington; Jean R. Hebeler, University of Maryland; Philip R. Jones, Wisconsin State Department of Education; June B. Jordan, CEC; Hugh S. McKenzie, University of Vermont; Herbert J. Prehm, University of Oregon; Maynard C. Reynolds, University of Minnesota; Herbert Rusalem, Teachers College, Columbia University; M. Angele Thomas, CEC; H. Rutherford Turnbull, III, University of North Carolina; and Frederick J. Weintraub, CEC.

- A guarantee of policies and procedures to protect the confidentiality of data and information.
- Assurance of the maintenance of an individualized program for all handicapped children.
- Assurance of an effective policy guaranteeing the right of all handicapped children to a free, appropriate public education, at no cost to parents or guardian.
- Assurance of a surrogate to act for any child when parents or guardians are either unknown or unabailable, or when said child is a legal ward of the state.

Throughout this paper reference is made to Public Law 94-142 and the potential impact this legislation could have in bringing about "full educational opportunities for the handicapped." This paper addresses the current areas of activity, concern, and developments essential to implementing a program to insure this goal. Specific topics to be addressed include:

1. *The Legal Right to Education*—Federal law mandates that shcool age children have the right to a free, public and equal educational opportunity. The challenge of implementation and monitoring of that law is now before the consumers and professionals.

2. *Financing of Education of the Handicapped*—Now when general school enrollments are decreasing and the public would like to keep costs from rising, special education is beginning to serve a new group of publics whose programs are most costly. The need exists to study the cost of different types of special education and their economic benefits.

3. *Delivery Systems*—The term "mainstreaming" with its varied meanings should well be replaced with the concept of "least restrictive environment." Delivery systems based on this concept offer placement on a continuum of services ranging from the least restrictive to the most restrictive environment. Individualization of educational plans is the key to educational placement.

4. *Early Childhood Education*—There is strong evidence that early stimulation and educational programing prevent handicapping conditions of high risk infants as well as markedly reduce the number of children who will need intensive or long term help.

5. *Educational Problems of the Severely Handicapped*—The right to education mandate opens the doors for children and youth previously denied this opportunity. Education must evolve responses to its complicated problems and many challenges.

6. *Career Education*—Unemployment and underemployment of the handicapped place serious responsibilities on public education. Career education's goal is to help a handicapped individual earn a living, but also to help that person live a life. Career education programs must be continually developed which are aimed at accomplishing this goal.

7. *Continuing Education*—A process of lifelong instruction is needed to equip individuals of all ages and in all disability groups to succeed in our society, to achieve self fulfillment, and to live at the maximum level possible.

8. *Personnel Requirements for the Education of the Handicapped*—Special education services have always been maldistributed but never so obviously as now, with the court mandates that all children be served. Current forces and trends are fostering role changes for special education personnel and increasing participation in interdisciplinary team approaches. New training approaches are needed.

9. *Research and Education for the Handicapped*—Research in this area has only been vigorous for less than a decade. Currently, there exists little dissemination of research, few coordinated research plans designed to meet the educational needs of all the handicapped, and only the beginnings of national plans to systematically implement proven methods or technologies of education.

10. *Public Information and Education*—Negative attitudes can be traced to lack of information, misunderstanding, or apprehension of how to deal with handicapped people. Information must be presented in a sequential meaningful fashion and disseminated in a systematic way.

Throughout the paper, as each of the above topics is addressed, the reader will note the recurring themes of the importance and role of parent and family involvement and the implications of the right to education mandate. Barriers or problems impeding implementation are identified. Creative and positive solutions must be found and action taken to insure all persons of their educational rights now and in the future.

THE LEGAL RIGHT TO EDUCATION

Establishing the Right

Only recently has it been established that handicapped school age children have the same rights as nonhandicapped students to a free, public, equal educational opportunity. The principal source of this right has been a large number of state and federal courts orders, which have been based on two premises: first, handicapped persons can learn and profit from training and education; and second, techniques and technologies exist which are believed to be appropriate for training and education the handicapped.

These premises have been transformed into legal doctrines by court decisions, which have stated that excluding handicapped children and youth from school violates their rights to education under state constitutions, the equal protection clause of the 14th Amendment, or the due process clauses of the 5th and 14th Amendments. Accordingly, courts have variously ordered that:

1. No handicapped child may be excluded from education because of his handicap (the "zero reject" principle).
2. Schools have a duty to provide an equal educational opportunity to all handicapped students (the "mandatory education" principle).
3. The preferred educational placement of handicapped students is in the least restrictive environment program (the "mainstream" belief).
4. The handicapped child is entitled to education or training that is appropriate to his needs and conditions and is designed to help him achieve his fullest potential (the "appropriate education" principle).
5. The child, his parents, and his guardian or a person acting as his parent (a "surrogate") are entitled to a hearing on any proposed special education placement before the placement is made (the "procedural due process" requirement).

Although litigation is the principal enforcer of this right, it is not the only source. Federal and state legislation also provides that handicapped persons have a right to education. This legislation often requires schools to comply with the principles of zero reject, mandatory education, placement in the least restrictive program, appropriate education, and procedural due process. It is also often accompanied by appropriations earmarked for special education. For example, Public Law 93-380 (the Education Amendments of 1974) and Public Law 94-142 (the Education for Handicapped Children Act of 1975) committed federal funds to the education of handicapped children and contained requirements of zero reject, least restrictive alternative placement, and procedural due process. By the same token, many states have recently enacted laws providing the same rights for handicapped students. Typically, federal and state guidelines, adopted by executive agencies, spell out in further detail how appropriations may be used and how the principles may be implemented.

None of the recent developments would have occurred without the vigorous and imaginative action of consumers and professionals committed to the education of handicapped people. They identified the sources of power and acted decisively to influence them. They brought lawsuits. They lobbied their state and federal legislative representatives. They entered into powerful alliances with state and federal agencies whose mission is the education of handicapped students. In short, they used each of the three available governmental processes and avenues of change.

Implementation and Monitoring

Consumers and professionals acted together to establish the right to education for all persons. Now the issues before those so concerned are the implementation of the right to education mandates and the monitoring of the actions of the schools.

The handicapped person's right to education is not yet fully implemented. The lack of manpower and financial resources and the reluctance of public schools officials to comply enthusiastically with the legal requirements pose serious obstacles to making the right meaningful.

Implementation is made even more crucial because of the complexity of the problem—integrating all handicapped students into a system of free public education and providing them with appropriate training. It is already clear that further legislation, executive rule making, and

litigation will be required before the right to education takes on substance for all handicapped children. Legislation, rule making, and litigation may all have to be used to create special programs, train competent educators, reallocate school dollars, provide early intervention programs, furnish compensatory training to adults, conduct child find activities of school age handicapped children, or prevent the use of discriminatory tests that lead to inapprorpriate school placements.

Monitoring the schools—making sure that they do as they are required to do—is an almost overwhelming task, one that surely will require resorting to the three avenues of change: third party monitoring, outcome oriented studies, and the cooperation of parents and other advocacy groups (for example, centers on law for the handicapped) and school officials (for example, professional associations of special educators). The resources of these groups, particularly their financial resources, are limited, which suggests that the monitoring process is likely to be more difficult than establishing the right to education or implementing it. However, all efforts should be made by the consumers and professionals to settle cases through the administrative levels before embarking on the route of the litigation process.

Promises of a Revolution

Finally, the right to education mandate promises to work a revolution both in public and private education in two major respects. First, the procedural due process requirement, coupled with the statutory requirement of Public Law 94-142 that each handicapped student have an "individualized" education plan prepared and carried out for him, will have schools functioning as child-centered institutions and will make them accountable for their work. Second, implementing and monitoring the right to education will affect the schools themselves. The resulting administration, organization, financing, and furnishing of special education will have a profound effect on the training and roles of all educators and on the education of nonhandicapped persons as well, particularly in those situations in which the handicapped and nonhandicapped individuals interact.

FINANCING OF EDUCATION FOR THE HANDICAPPED

"Money does not educate children; teachers and other educational workers do. Spending money on education will not in itself guarantee that children will be educated, but it is certain that children cannot be educated without it." So said David Selden (1971), the then President of the American Federation of Teachers, in his testimony before a U.S. Senate Select Committee investigating equal educational opportunity for every citizen of the United States.

Existing State Legislation

It is the states' responsiblity to provide each individual with an appropriate and equitable education, and states are allowed freedom and autonomy in making their individual rules and regulations. In the 1960's most states had legislation merely permitting local programs for the handicapped. The typical state legislation made provisions only for children classified under traditional categories. By 1972, 41 states had changed their legislation into one of the following forms of mandatory law (Trudeau, 1972);

1. *Mandate by petition*—which means education is offered only when a substantial number of parents and advocates petition the school board.
2. *Selective mandate*—which discriminates among the exceptionalities, for example, mandating the provision of services to the emotionally disturbed but not to the learning disabled.
3. *Conditional mandate*—which stipulates that education for certain categories of children would be compulsory if certain conditions were met, for example, a requirement of at least 15 children of a certain category living within one school district.
4. *Planning mandate*—which requires that a state develop plans, possibly including a future deadline for serving its exceptional children.
5. *Full mandate*—which forbids the exclusion of any child regardless of the educational need ("zero reject").

By 1975, the number of states with mandatory laws had grown to 48, with an increase in the number of states having the full mandate (Bolick, 1975).

Despite this additional mandatory legislation and the wide array of legal action pointing toward the urgency of educating exceptional children, the U.S. Office of Education estimates that only about 40% of the handicapped are currently receiving the assistance they need to have full equality of opportunity (Jones & Wilerson, 1974). An analysis of state financing of services for the handicapped (Thomas, 1973b) has shown that the most frequently served individuals have often been those whose educational costs were lower than other handicapped groups. Further, strong legislation has generally only been carried out in the wealthier states. Thus it would appear that legal mandate alone is insufficient to guarantee programs for handicapped persons.

The Fiscal Implications of Federal Right to Education Legislation

The right to education for all persons now requires school systems to provide for additional exceptional students at a time when the general school enrollment is declining. Although the number of these "new" pupils to be served is low, the education of this particular population of handicapped students will be more costly than that of handicapped students already being served (Bernstein, Kirst, Hartman, & Marshall, 1976).

The previously unserved and underserved, who must now be provided an education, include the severly, profoundly, and multiply handicapped. The complexities of their handicaps require the employment of specialists, such as communication specialists, physical and occupational therapists, dieticians, and nutritionists. In addition to providing education, school agencies must also deliver related services such as prosthetic devices, adaptive transportation, equipment, and special teaching materials. Developing individualized plans and determining solutions for the unique problems of each individual will require multidisciplinary staff planning which will create additional costs. Also, school districts must now develop infact, preschool, and early intervention programs, and also programs aimed for persons needing education through at least the ages of 21(and in some states an even higher age.)

One of the stipulations of Public Law 94-142 is that the student be educated in the least restrictive environment. Experience has shown that regular class placement with supporting services is not automatically less costly than educating children in self contained classrooms. Administrators must hire consulting teachers, methods and materials specialists, itinerant teachers, and resource teachers and must pay for inservice training of regular classroom teachers. Other examples of additional costs are the installation of special audiological equipment in any classroom a hearing impaired student needs to attend or the installation of ramps or elevators in schools accommodating orthopedically handicapped students.

Methods of State Fiscal Support

The question now is not whether, but how, special educational services should be financed. There are six general categories of state fiscal support. These are intended to at least partially offset the additional costs incurred in educating some handicapped students. While the amount and distribution of the reimbursement varies from state to state, the following definitions supply the basic principles upon which the formulae are built (Thomas, 1973a; see Appendix B for further elaboration of these definitions):

1. In the *unit financing* approach, school districts are reimbursed a fixed sum by the state for each designated unit of classroom instruction, transportation, administration, or ancillary service.
2. Through the *weighted formula* system, for each handicapped person a school district enrolls, it is reimbursed the cost of educating a nonhandicapped individual, multiplied by a predetermined factor. This factor may vary according to the type or degree of disability of the handicapped student.
3. With the *percentage reimbursement* system, a percentage of all costs (sometimes the entire costs) incurred by school districts in educating handicapped individuals is assumed by the state.
4. In a *reimbursement by personnel* approach, the state pays for any special staff costs that are incurred by a school district offering programs for handicapped persons.
5. In the *straight sum reimbursement system*, a set amount of money is distributed from the

state to the school district for each handicapped child placed in an approved program.

6. School districts using an *excess cost formula* determine the per pupil cost of educating a handicapped child and then subtract from this amount the cost of educating a nonhandicapped child in the same district. The difference or excess is then reimbursed by the state.

None of the above support systems is immune from inherent deficiencies. Under the unit financing system, rural or small school districts often do not quality for unit size. The weighted formula system is limited in two respects: first, if the per pupil cost used is a state average, those districts with high educational costs will not receive equitable reimbursement; and second, the system assumes that all individuals in a given disability group will require the same amount of funding. In percentage reimbursement school districts are tempted to place children in the least expensive program. Reimbursement by personnel fosters special class placement rather than regular class placement with additional appropriate resource services. Further, it encourages large class sizes to decrease per pupil expenditure. The straight sum system accentuates labeling. And lastly, in the excess cost formula, it is difficult to ascertain exactly what constitutes excess cost.

Special Factors Adding to Costs

While concerns of programming, cost, funding, and management cut across all special education services, certain geographic locations or particular populations have unique problems due to an unusually high proportion of individuals having special needs. For example, the military assigns personnel with dependent handicapped children to installations in areas where educational programs for the handicapped are available (the "compassionate transfer program"). Consequently, the entrollment in these programs exceeds the expected enrollment (according to prevalance estimates) and adds greater financial burdens to the school districts involved (Jones & Wilderson, 1974).

A child's handicapping condition is rarely confined to academic concerns: it also affects the child's parents, his relationship with peers, and the coordination of efforts on his behalf among nonschool agencies. For this reason, a comprehensive special education program within the public schools should include elements of a noneducational nature, such as infant screening and identification; parent counseling; and liaison with medical and mental health services, university clinics, residential institutions, and other private and community agencies (McLure, Burnham, & Henderson, 1975). The costs of these services have not traditionally been part of school budgets.

Public Attitudes and Accountability

The public attitude, despite the wishes of many of those directly concerned, is that costs shall not rise. There is the question of whether the handicapped, particularly the severely handicapped, should receive high expenditures of monies because they may not have the potential to benefit from such expenditures. Such thoughts do indeed exist and are sometimes expressed publicly even though the meaning may be disguished behind other language (Sherr, 1975).

However, reflecting the increased scope of available services, state and local outlays for special education in most states have expanded two to three times over the 1972 levels (Wilken & Callahan, 1975). Public decision makers, because of the public attitude towards costs (though not necessarily the education of handicapped persons), are growing increasingly uneasy with spiraling costs of special education (Yates, 1975). Therefore, it is reasonable to expect that these decision makers will require greater accountability on how funds are delivered and expended, how well the program objectives are met, and how beneficial the results seem.

DELIVERY SYSTEMS MAINSTREAMING

Delivery Systems for All Children

The mandate to provide the education of all children regardless of handicapping conditions is here, and every school system must accept each child as its legitimate educational concern. Statements of exclusions must be eliminated. "A different climate is reached when it is assumed that all children are capable of being educated than when it is assumed that just some children have this capability" (Bertness, 1976).

A school system which, almost 18 years ago, successfully adopted the position of including children with handicaps as opposed to excluding them, offers some statements on the issue:

- Education of exceptional students should be an integral part of the total program of public education.
- Programs should emphasize similarities of exceptional children to other children.
- A concern for the education of exceptional children seems to demand a concern for all children.
- An exceptional student's education plan draws increasingly on the general public education resources as he becomes master of his exceptionality.
- Provisions for handicapped students must be made in all remodeling and new construction.
- The philosophy and elements of the program should be stressed in personnel recruitment, since not all educators have the same convictions.
- The advantages of the program will need to be explained and sold continuously as community and staff memberships change.

"When we work seriously with all children, we accept them with the characteristics they possess rather than some characteristics we might hope exist. A school, therefore, becomes a complex, dynamic place, loaded with many varied programs responding to the great variety of multiple and changing pupil characteristics. It is not enough to say we belive in education for all children, we must demonstrate the belief through actions" (Bertness, 1976).

Mainstream—A Belief

In formal session, April, 1976, the Delegate Assembly of The Council for Exceptional Children officially adopted the following definition on maintstreaming:

> Mainstreaming is a *belief* which involves an educational placement procedure and process for exceptional children, based on the conviction that each such child should be educated in the least restrictive environment in which his educational and related needs can be satisfactorily provided. This concept recognizes that exceptional children have a wide range of special educational needs, varying greatly in intensity and duration; that there is a recognized continuum of educational settings, which may, at a given time, be appropriate for an individual child's needs; that to be maximum extent appropriate, exceptional children should be educated with non-exceptional children; and that special classes, separate schooling, or other removal of an exceptional child from education with non-exceptional children should occur only when the intensity of the child's special education and related needs is such that they cannot be satisfied in an environment including nonexceptional children, even with the provision of supplementary aids and services.

Least Restrictive Environment

Delivery systems employing the least restrictive environment concept must focus on a full continuum of services. Educational environments are viewed along a continuum of physical and social restrictiveness from placement in a regular classroom with nonhandicapped peers to placement in a more restrictive setting such as a special class (on a full or part time basis), a special school, a group home, or a residential institution.

Exceptional persons have a wide range of special educational and related needs that vary greatly in intensity and duration. Given this diverse range of needs, both specialized and generic delivery systems are necessary. However, to the maximum extent appropriate, handicapped students should be educated with nonhandicapped students. Placement in special classes, separate schooling, or other removal from education with nonhandicapped students should occur only when the intensity of the student's educational and related needs is such that they cannot be satisfactorily provided in regular programs, even with the use of supplementary aids and services.

Special Services That Support the Delivery System

To support any instructional delivery system there must be an array of special service. These include all types of services necessary for comprehensive education of a pupil. As teachers individualize instruction for pupils, and as schools provide more instructional services for individual pupils, there must be an effective system for delivery of special information and materials to teachers and pupils. Other special services include special transportation, special seats, electronic communications equipment, counseling and guidance, and a variety of consultative services (Partridge, 1976).

Parent Involvement

The recent state and federal court actions insuring the basic rights of parents will affect the delivery service to their children. It has now been established that:

- Parents should be informed about educational provisions for handicapped students available to them.
- Parents have the right to appeal a decision that would alter their child's educational program.
- Parents have the right to review and use in their appeal all information used by the school to make the decision.
- Parents have the right to have a neutral party decide on the most appropriate program for their child.
- Parents have the right to have the benefits of a special program specified and evaluated.

An essential element of any delivery system is parental involvement. Parents may be more appropriate trainers of very young persons than educators outside the home. In addition, parent training programs may be less expensive than educational centers. The participation of parents in educational staffings helps insure that legal rights of the child or youth are protected. Such participation also offers the opportunity to establish a positive relationship betwen the program and the home.

There are numerous other reasons to involve parents in their child's educational input (Shearer & Shearer, 1976):

1. Parents are, in some cases, the most appropriate trainers/educators.
2. Parents are the consumer; either directly or indirectly they pay for the program and service their child is receiving.
3. If knowledgeable about the program, parents can be the best advocates for it.
4. Parents of a handicapped child will have more responsibility for their child over a significantly longer period of time than parents of a nonhandicapped child. They need parenting and teaching skills in addition to those needed by parents of nonhandicapped students.
5. Parents know their child better than anyone else and can serve as a vital resource to program staff.

EARLY CHILDHOOD EDUCATION

No one is sure of the exact number of handicapped children and youth in the United States today. This is particularly true of children under 6 years of age, but the usual estimate for this group is about 1 million. No matter what the number, there is ample evidence that the number could be reduced through proper education.

Major longitudinal studies now offer evidence that high risk infants can achieve adequate school success when favorable social climate and positve parenting techniques are used (Werner et al., 1971). Equally supportive of the need for early stimulation is the evidence that, when infants who suffer perinatal stress are not offered early training, all of these children are classified as handicapped by the age of 10 (Werner et al., 1971).

Factors Contributing to the Number of Handicapped

The United States ranks 14th in infant mortality, behind 13 other industrialized nations (DeWeerd, 1976). The mortality rate is higher among proverty groups, which suffer from poor housing, inaequate medical services, and malnutrition. There are also a high number of handicapped children who reside in low income families. According to the Census Bureau, 14.2% of all children, or one out of seven, was living in poverty in 1973 (Bureau of the Census, 1976). A family's level of income affects the environmental conditions of a child's life. The quality

of these inputs, such as the food consumed, affect a child's growth and development. Deprivations imposed through undernourishment (often a result of poverty) produce deficits in the brain cells as well as structural and functional distortions in growth (Dobbings, 1975).

Another indication of the problem is a study conducted in 1970 and 1971 by doctors in Washington, D.C. (DeWeerd, 1976). On a representative sample of 1.436 families with children between 6 months and 11 years, it was found that 26% of the children between 1 month and 3 years had iron deficiency anemia, 26% had uncorrected or inadequately corrected visual disorders, and 18% suffered from partial hearing loss with nearly another 13% having ear infections that could lead to hearing loss. These children came from all socio-economic levels and were receiving health care. The doctors making the study felt the situation was probably no different in other cities. Add to this picture the increased prevalence of single parent families, child abuse, and economic distress, and it puts the child, and particularly a handicapped child, in a most vulnerable position.

There is ample evidence, however, that programs that provide for early stimulation and educational programing to meet the critical needs of young handicapped children and their families are reducing the number of children who will need intensive or long term help (Karnes, 1973: Haring, 1976). Some of the major factors remediating handicapping conditions are the techniques the caretaker uses to work with the infant. The most effective programs with infants include specific training of the child's caretaker. The importance of reaching handicapped children early and working to help them reach their full potential cannot be overstressed. Without early help these children are, in many cases, lost. With help, they can prosper and often reach a potential one could not have dreamed years ago (DeWeerd, 1976).

Federal Impetus to Finding and Serving the Young Handicapped Child

Currently, only about 40% of school aged handicapped children receive appropriate specialized educational services. The estimate for preschool children is only about 25%.

Recent court rulings and new legislation, however, are helping to move forward the goal of full services. Public Law 94-142 requires states to provide education to all handicapped children between the ages of 3 and 21 by 1980 (with the reservation that states not offering programs to nonhandicapped individuals between the ages of 3 to 5 and 18 to 21 are permitted, though not required, to provide educational services to handicapped individuals in those age groups).

Another good example of recent developments is the Handicapped Children's Early Education Program, generally known as the "First Chance" program. Administered by the Bureau of Education for the Handicapped, the program grew from 24 initial projects with $1 million appropriation in 1969-70 to a projected $22 million for about 200 projects in 1975-76. The purpose of the First Chance program is to develop demonstration projects. These serve as models for public schools and other agencies who need information on how to provide a variety of kinds of special help for handicapped children and their families.

In a review of the First Chance Projects, Karnes and Zehrbach (1976) identified four major delivery systems used in the programs for young handicapped children: the home-based system; the home followed by center; the home and center-based system; and the center-based system. Home-based systems are those programs that are delivered entirely in the home. The parents are generally viewed as the primary change agents, but in a few programs professionals or paraprofessionsals provide tutoring or direct teaching. Many home-based programs, which begin with children under 3 years old, continue as center-based programs after the children are over 3 years of age. Other programs combine both the center and home approaches. The children usually attend a program delivered primarily in a center, and the parents are trained at home to deliver the program. These programs are characterized by frequent staff visits to the homes and cooperative planning to coordinate center and home activities. In strictly center-based programs, the emphasis is on teaching parents at the center. Carryover to the home is encouraged, but in many instances only infrequent visits are made to homes by the staff. These center-based programs tend to be for the older preschool child and/or the more severely handicapped child who can benefit from special

equipment and highly trained personnel. Many of these systems involve the use of categorical grouping but there is an increasing emphasis on the inclusion of handicapped children in programs with nonhandicapped children.

Major Problems in Early Childhood Education

Now that the federal government has encouraged early education of the handicapped through legislation and funding, several critical issues need to be considered. Each handicapped child in the state aged 3 to 5 who is counted as served will generate a special $300 entitlement. This should tend to alleviate some of the additional costs that preschool programs for the handicapped incur. For example, in an analysis of programs in Bloomington, Illinois, the amount of extra cost per handicapped preschool pupil was $3,005, or 4.22 times the cost per elementary regular pupil (McLure, Burnham, & Henderson, 1975, p. 14).

A. *Timing of services*: Mandatory assessment and identification of handicapping or potentially handicapping conditions should begin at birth or shortly thereafter. As a followup, "mandatory infant learning programs, based on demonstration center programs, should be available to begin developmental intervention for the child" (Sontag, 1975). "The earlier, the better" seems to be a safe maxim, especially for multiply handicapped children since the need for early stimulation is so great.

By providing appropriate learning experiences starting in early infancy and by continuing these experiences throughout the preschool years, it is possible to take advantage of critical or optimal learning periods (Horowitz & Paden, 1973). These may be thought of as developmental intervals when a child may be most able to learn certain skills. Also through early intervention, the cumulative and compounding effects of deficits can be reduced, even avoided in many cases. The very first approximations to appropriate developmental responses can be noted and built upon. If the child's environment is devoid of stimulation or filled with stimulation too complex for the child to process, the development of bizarre responses is inevitable. The most severely handicapped child is learning all of the time—learning good responses or poor ones, or learning not to respond at all.

B. *Child find activities*: In October 1974, the National Assocation of Director of Special Education conducted a national survey to identify those child find systems currently operating in the states. Of the 26 state programs identified, 13 reported that their target populations for child find included the preschool age child (*Child Find*, 1975, p. 60). Current federal legislation stipulates that state departments of education must develop plans to assure extensive child identification procedures.

C. *Family involvement*: The first hand involvement of parents in the teaching of their handicapped child is important if the child is to learn to function in his everyday environment. To be maximally effective, parent and infant training should start shortly after birth. In one of the model First Chance programs, the parent and infant come in together starting 3 to 5 weeks after the birth of the handicapped child. During each weekly session, the infant's progress is reviewed in terms of motor, cognitive, and social development; remedial exercises and training procedures are demonstrated; and the parents are taught to continue the program at home for the ensuing seven days (Dmitriev, 1974).

Other examples of family involvement developed and practiced in the First Chance programs include participation of the parent as an administrator, disseminator, staff member, primary teacher, recruiter of children, curriculum developer, counselor, assessor of skills, and evaluator and record keeper (Shearer & Shearer, 1976).

It must be remembered that being the parents of a handicapped child is a responsibility that taxes family members physically, emotionally, and financially. A parent of an autistic child suggested that parents of handicapped chidren "burn out"—so much is demanded of them in simply meeting the everyday needs of the child and the family that they have no energies left over for carrying out teaching programs (Sullivan, 1976).

If families are to be involved in providing their handicapped infants and children with good developmental learning experiences that run concurrently and complementarily to the preschool program, then families must be provided with a range of supporting and respite services: trained sitters to allow the rest of the family opportunities to do things together; housekeeping and even laundry assistance in the

case of incontinent or bedredden children; a variety of flexible day care facilities; and live in facilities where a handicapped child may stay for a few days at a time during a family crisis or family holiday.

It is unrealistic to expect young handicapped children to develop at their best possible rate if parents, siblings, and peers are not involved in their education. Yet it is equally unrealistic to expect such involvement unless parents are provided, from the start, with various kinds of relief and assistance.

D. *Handicapped/nonhandicapped mixes*: The coeducation of the handicapped with the nonhandicapped is desirable if it is in the best interests of the handicapped person. This arrangement is especially important for very young children. They should be enrolled in the least restrictive preschool environment as close as possible geographically to their own family and community setting. The first 6 years are the years when the basic social, cognitive, and motor skills are most likely to develop. These emerging skills have a greater chance of resembling those of the normally developing child if the handicapped child can be in an integrated preschool setting. Most handicapped young children, even the severely handicapped, can be successfuly integrated without undue strain on the program (Gold, B., 1975). Certainly, for the majority of handicapped children, it is not necessary to radically redesign the environment (Allen, 1975); however, if new facilities are on the drawing board, the omission of certain architectural barriers and the selection of developmentally appropriate design, furnishings, and equipment would make it a more desirable facility for *all* young children, handicapped or otherwise.

E. *Staff*: Radical redesign of preschool staffing patterns is not necessary either, although the number of handicapped children and the severity of their handicapping condition must, of course, be taken into account. One adult for every 3 to 5 children is usually a comfortable ration (Moore, undated).

What is more important, though, is the quality of attention that is provided. The staff should be composed of teachers and aides who understand developmental processes and individual differences, who can program for each minute step taken by the handicapped child, who can deal with biological and behavioral dysfunctioning, and who can work as reciprocating members of an interdisciplinary team. Many authorities recommended that all teachers of young children have as a part of their training, opportunities for firsthand practical interactions with physical and occupational therapists, nutritionists, communication specialists, psychologists, and specialists in other disciplines related to the developing child (Connor, 1975; Bricker, 1976; Allen, Holm, & Schiefelbusch, in press).

F. *Curriculum*: There are a number of sound and well tested preschool curriculum guides and models available for use with young handicapped children (for example, Harbin & Cross, 1975; Myers, Sinco, & Stalma, 1973; Hart, 1974; Schattner, 1971; and Shearer, 1972). Research has not identified any one curriculum approach as being superior to any other, but there are certain components that set successful programs apart from unsuccessful ones. These components include a commitment of the staff to a given approach, a high adult to child ratio (1 to 3 for handicapped children), concurrent inservice training, attention to individual differences, strong emphasis on language development and cognition, involvement of staff in curriculum development, broadly based curricula that foster the development of the total child, family involvement, and appropriate instructional materials and equipment (Karnes, 1973).

In selecting an appropriate preschool curriculum it is important to choose one that allows each child to become actively involved in a wide range of enjoyable activities that provide him with the appropriate sensory and social feedback. The curriculum must also plan for acquisition of a variety of specific skills. The self-help skills are especially important since handicapped children cannot survive without them in any but the most restricted environment. On the other hand, the teaching of self-help skills should not dominate the program; there must be equal emphasis on the acquisition of other basic communication and developmental skills and provision for activities that relate the various developmental areas. To accomplish this, the handicapped child must be provided with those experiences basic to learning for all children which he is not likely to encounter:

1. He must be given many opportunities to explore the environment since he will probably be deprived in several areas of sensory stimulation.

2. He must be provided a strong physcial education component.

3. He must have a structured program of play activities with peers, which recognizes that the most rudimentary of play behaviors will need to be taught.

4. He must be supplied with an intensive and carefully sequenced communication program built upon even the most remote of first approximations to preverbal communications responses.

Evaluation. Every early childhood education program must contain systematic procedures for observing, recording, and reporting child and group progress. Only by keeping such records can there be useful feedback for teachers and family, improved staff communication and relationships, and accurate information upon which to plan and make valid decisions for each child and for the group as a whole.

The Critical Early Years

The early years are truly the years of educational payoff. Today's severely handicapped infants, toddlers, and preschoolers need not fit that category 5 or 50 years from now; being handicapped does *not* imply a static condition, but rather a developmental process much like growth itself. Through the specialized assistance in a dynamic rather than a static learning environment, young handicapped children are provided the opportunity to attain their full potential.

EDUCATIONAL PROBLEMS OF THE SEVERELY HANDICAPPED

Any discussion of the educational problems of severely handicapped persons must begin with the recognition that many of these problems and needs are *not* unique. For instance, severely handicapped persons, like nonhandicapped persons, have the right to an education and need that education to be individually and appropriately tailored. Severely handicapped persons are not unique in needing positive response from other—affection and attention—within and outside the educational setting. They are not unique in needing barrier-free access to education, with removal of attitudinal barriers as well as the more obvious physical ones. Severely handicapped students are like other students in needing opportunities to explore the natural and man-made environment and, through education, to acquire the skills that make such explorations meaningful and enjoyable. Severely handicapped students are not unique in needing to participate in social relationships and activities, both in and out of school. They need to interact with nonhandicapped persons who can "model" certain kinds of behavior for them to learn. Handicapped persons need all of these experiences in an environment where differences are reduced and mutual tolerance—and appreciation—is increased.

The term "severely handicapped" as used here refers to persons who have multiple impairments or impairments of such severity that they require extraordinary assistance in educational and other life situations. Included in this group are persons who have spent the major portion of their lives in public institutions and who are now being placed in the community. Many of these persons have had no education and pose special problems to local educational systems.

By definition, the impairments of severely handicapped people have more intense and pervasive effects; their problems are more complicated than are those of mildly or moderately handicapped persons. Yet whether one can say with assurance that these problems are so qualitatively different as to be unique or that, instead, they are merely exaggerated versions of other problems, is a moot point. Rather, precisely because the problems are complicated and present so many challenges, educators are evolving unique responses. Moreover, educators along are responsible for devising these strategies, adaptations, modifications, and procedures; no other professional group has been told in a legislative mandate to turn around decades of neglect and mismanagement of this population. The leadership exerted by the Bureau of Education for the Handicapped (HEW) has greatly facilitated development of these responses.

Factors Influencing the Design of Educational Strategies

When federal legislation, Public Law 94-142, is fully implemented, the country's severely handicapped children and youth will achieve full realization of their right to an education, a right traditionally denied rather than granted. For

educators the legislation is also promising because it affords opportunities to observe students, collect information, increase understanding, and sharpen skills related to teaching a population that is new to the classroom. We need to keep reminding ourselves that management of severely handicapped persons has only recently become an educational rather than merely a custodial concern.

The following are some of the factors now taken into account as both pupils and teachers reap the benefits of the legislative mandate.

A. *Early recognition of handicaps*: Most severely handicapped children can be recognized as severely handicapped shortly after birth. The full extent of their impairments may not be known for some time, and prognostic statements may have to wait for extended information collection. However, these persons *can* be identified in early infancy and be referred immediately to appropriate educational and other services.

B. *Early provision of services*: The earliest possible referral to services is urgent. It is now clear that the earlier individualized educational planning begins, the greater will be the gains students make in performing all skills. The most effective time to start educating severely handicapped persons is at birth, and the benefits of starting this intervention early accrue not only to the infant but to parents as well.

C. *Probability of multiple problems*: Severely handicapped persons are likely to have multiple problems that require the input of specialists from several disciplines in the classroom. The mode of delivery should not be a critical problem for the school age child. Classroom teachers can, in some cases, be trained to deliver some services traditionally offered by other specialists; at other times, the specialists will perform these interdisciplinary services. What is crucial, however, is that this input be available and that it be integrated into the classroom program. At the very least, the following specialists (representing several disciplines) must be intensively involved in education and planning for severely handicapped children: medical specialists, language and communication disorders specialists, developmental specialists (for instance, occupational or physcial therapists), and family, home, and community specialists.

D. *Need for lifelong attention*: Severely handicapped persons are likely to have problems that require lifelong attention from others. It was pointed out earlier that educational intervention should begin for these persons at birth. The continuation of that statement is that educators must be involved in planning and coordinating the comprehensive, lifelong management of severely handicapped persons. Schools represent a community based organization with the facilities and resources to perform these functions intelligently, with minimal administrative shuffling.

E. *New skills needed by educators*: Educators of severely handicapped persons require specialized training because they need many new skills. The skills fall into at least four categories.

The first category concerns the precise, systematic arrangement and presentation of instructional cues. Early attempts to educate severely handicapped students failed because they began with instructional steps that were too broadly defined. Expectations were too high at the beginning of the instructional sequence, and there was disappointment when the pupils failed to "cope" with those steps. Learning steps must be sliced more "finely"—what where formerly considered beginning skills may in fact be the end product of many prerequisite skills. Current educational technology permits teachers to analyze the skill they will be teaching so closely that they can break it into as many components as are necessary for teaching that skill to any child.

The second category of new skills is that concerned with competence in new subject matter. If educational intervention for severely handicapped persons must begin early, the "curriculum" will be different from traditional school programs. The instruction will include skills or behaviors that occur in infancy: the most basic self help skills, the earliest motor and cognitive skills, and so on. What is important to remember, however, is that these skills may often be part of the curriculum for older children who have not participated in an educational program before. For them, too, teacher will need to teach such basic skills as making eye contact and using muscles that have not been trained. This represents a significant departure from conventional topics for most public school teachers.

The third category of skills deals with data collection and measurement. Because education for severely handicapped persons is such a new

concept, there is little reliable information about what severely handicapped persons can in fact learn. Further, there are no standardized curricula or teaching procedures that have been adequately tested under controlled conditions. For these reasons, it is urgent that teachers know how to collect measurement information about student performance and how to analyze this information with a view toward improving instruction. The most basic considerations are whether or not a pupil is making progress and whether or not an instructional program is working. There is no way to guess at the answers to these crucial questions.

The fourth category of skills is in the area of working with other specialists and working with parents. Several conventional practices are being abandoned as teachers instruct severely handicapped pupils. The traditional "boundaries" once protected by different disciplines are now being crossed. This is happening for reasons that have been discussed earlier: the problems are simply too complex to permit narrow, fragmented attacks on them. Also, the practice of having parents at school only for PTA meetings or scheduled conferences is giving way to a much more intensive and meaningful involvement by parents in the management of the various aspects of their children's education. With training by teachers, parents can increase their competencies and can continue at home the instructional programing begun in school. That carryover is critical for severely handicapped pupils. What is implicit in all of the above is that teachers must now have skills for working with adults, who may be as new to classroom involvement as is the new population of students.

F. *Support for parents* Professionals need to offer support and training to parents from the moment the severely handicapped child is identified. Particularly during the crucial early months of a child's life, when the parents are struggling to accept the child's impairments and face so many problems, a total support system is needed, the kind of support that encourages the parents to look positively at what they *can* do for their child. Keeping a child at home is no easy matter. Parent training thus becomes an essential part of the total planning for severely handicapped children. An untrained, unprepared parent can easily become overwhelmed and decide to place the child in an institution in spite of tremendous ambivalence about such a decision. It is critical that arrangements be made for continuing assistance, for respite care, for information dissemination (for instance, newsletters such as *Closer Look,* published by the National Information Center for the Handicapped, Washington, D.C.), and for other aspects of a long term support system.

G. *Focusing on society's goals*: Educators need to participate in sorting out society's goals for severely handicapped persons. Society has never articulated—or been forced to articulate—*positive* goals for the severely handicapped. Of course, one can infer earlier negative goals: Severely handicapped persons were to be isolated from society, stored in instiutions. That is no longer legally or morally defensible. Society's goals are emphasized here precisely because schools are social institutions whose purposes usually are decreed by the particular society. Schools are thought of as the places where students receive an apprenticeship for full participation in adult society. Educators are now looking critically at what is being done to prepare these new students for that role. Vocational training, like education, has been generally withheld from severely handicapped persons. Yet recent experiments with training young adults (Bellamy, Peterson, & Close, 1975; Gold, M.W., 1972, 1975; Mithaug, 1976) have shown that positive results can be achieved—that most severely handicapped persons can perform tasks or provide services that are marketable in modern industry. These results also indicate that curriculum planning must introduce prevocational training early in a person's education.

Changing Community Attitudes

It is insufficient to speak of particular factors affecting educational planning or even of something so global as a society's goals. What underlies everything discussed here is the necessity of a basic change in community attitudes toward a population that is usually hidden from view. It is virtually impossible to plan a community based intervention—including alternative living arrangements, comprehenisve lifelong support systems and management, or even help to parents—without a fundamental willingness to reverse old attitudes and to open the community to handicapped persons. That means many

different accomodations. Physical and architectural changes are needed to make community resources accessible, something so simple as modifying a telephone booth, for instance, Psychological accommodations are required so that severely handicapped persons (who may look and act differently than other people) are welcomed kindly and intelligently in the community's meeting and business places and are helped wherever necessary in using its resources and recreational facilities. Design of community facilities should be as "normal" as possible to minimize stigma and isolation.

The way to change a community's attitudes is to keep severely handicapped people *in* the community and to demonstrate the effectiveness of education in enabling these persons to function well. Success generates more success.

But one final note—for some people, the very success of severely handicapped persons as they become integrated into the life of a community may be as disturbing as is their presence there. Competent functioning of this kind startles some people; it upsets their biases and stereotyped views of "the handicapped. The point is, simply, that changing attitudes is the most difficult and complex problem of all—and it is the one most in need of solving.

CAREER EDUCATION

Career education is an area of study within the total school curriculum that is concerned with the future occupation of the individual. In the past decade, career education for handicapped persons has been a topic of concern but not of signficiant action. In a 1973 paper, C. Samuel Barone presented the following data about the approximately two and a half million handicapped youth leaving the school systems in the four years to come. About 525,000 (21%) will either be fully employed or be enrolled in college; 1 million (40%) will be underremployed and at the poverty level; 200,000 (8%) will be in their home communities and idle much of the time; 650,000 (26%) will be unemployed and on welfare; and 75,000 (3%) will be totally dependent and institutionalized. Such predictions raise grave concerns both for those who are involved in career education and those who are interested in the welfare of the handicapped.

The prediction that 1 million young handicapped persons will be underemployed is particularly serious, for underemployment means that the person possesses a greater degree of productive capacity than his or her present task demands. To predict that this will be the fate of 2 out of every 5 handicapped persons leaving the school system can only be considered as a serious indictment both of the educational system and of the larger society. For too long society has assumed that a handicapped person should be both pleased with and grateful for any kind of work society provided; that for a handicapped person, boredom on the job is impossible; and that while most persons have a right to seek work compatible with their interests and aptitudes, such considerations do not apply to the employment of handicapped persons.

Career Education for the Handicapped

Although fundamental principles of career education are common to all citizens, handicapped citizens both contribute and need some distinctive shifts in emphasis. Career education's emphasis on strengths and assets, its refusal to emphasize failure and shortcomings, and its avoidance of diagnostic labels and stereotypes seem to hold a positive potential for handicapped persons who all too often are made well aware of their limitations and in the process are limited in discovering their talents.

The diversity of skills and differing capacities for independent functioning found in the general population is even greater in the handicapped population. Some individuals who have severe and/or multiple handicaps will be limited in the kind of activity and in the degree of personal independence possible to them. The responsibility of public education is to provide experiences and to organize these experiences in such a way that they are relevant, meaningful, and appropriate.

While some entry level skills for some handicapped individuals are stressed in the vocational aspect of career education, the focus should be on personal skills, work attitudes, and flexible work habits so that an individual can be fairly readily retrained or can adjust to the constantly changing occupational market. For selected handicapped students at the secondary level and all handicapped individuals at the postsecondary level, the development of technical skills is an

important prerequisite for job entry. For handicapped individuals, such preparation may enable them to practice a profession, to be employed in a sheltered workshop, or to take care of their basic needs in the home.

The Scope and Goals of Career Education

Kenneth Hoyt, Associate Commissioner for Career Education in the U.S. Office of Education, has indicated that "career education is the total effort of public education and the community to help all individuals become familiar with the values of work-oriented society, to integrate these values into their personal value systems, and to implement those values in their lives in such a way that work becomes possible, meaningful, and satisying to each individual" (Hoyt, Evans, Mackin, & Margum, 1974). In Hoyt's framework and in most of the literature concerning career education, "work" is defined as a conscious effort to produce benefits for oneself and/or others. Both paid work and unpaid work are included in this concept, which speaks to the need of all persons to be productive as well as to find meaning in their lives through their own accomplishments.

In further exploring the concept of career education, some premises common to both handicapped and nonhandicapped persons emerge:

- Since both "career" and "education" span preschool through retirement, career education must also span the entire life cycle.
- The concept of productivity (including both paid and unpaid activities) is central to the definition of work and career education. Thus work includes the activies of the student, the homemaker, and the volunteer.
- The degree of independence an individual can exercise and the degree of his/her skill in terms of vocational or occupational activities varies; the goal of career education is to assist each individual in achieving the optimum.
- Career education extends that which students are asked to learn at school to the world of work. Basic academic skills, a meaningful set of work values, and good work habits represent adaptability tools needed by all persons who choose to work in today's society. A basic principle of career education is the emphasis on a person's successes, accomplishments, attainments, not on failures or shortcomings.
- Career education provides individuals with skills and concepts and a concept of themselves, so that they can more readily cope with change and modification. Sidney Marland (1971) defined career education as a "broader understanding of the purposes of education in today's highly sophisticated, technical, change-oriented society."
- Studies have established that most individuals will experience three to five fairly signficant occupational shifts in their lifetimes. One of the responsibilities of the educational system is to help provide the readiness for coping with such changes. Career education thus helps society support individuals in getting and finding other necessary or desirable employment and in securing appropriate training or retraining.

Agents of Career Education

While education bears a mandated responsibility for career education of the handicapped, other parts of society have particular and valuable contributions to make.

A. *The business community*: The business/labor/industry sector of our community is an integral part of career education. Some of the contributions that this sector can offer include providing work experience and work-study opportunities for students and for those who educate the students (teachers, counselors, and school administrators); serving as career development resource personnel to teachers, counselors, and students; and participating in part time and full time job placement programs, in career education policy formulation, and in curriculum development.

Career education programs that merge education and the world of work in a practical sense help to minimize misinformation, unfounded fear, and reticence on the part of employers. When employers are involved in the curriculum development of career education programs and when they are working with students in school and in their places of employment, they begin to deal with individuals and are less likely to categorize the handicapped or to generalize about their career potential.

B. *Family*: The attitude of the family is most significant in the career development of the handicapped. Because of a greater sense of his special physical, emotional, or intellectual needs, the handicapped person often is treated by his family as a very dependent individual. Family expectations for the handicapped individual frequently are significantly lower than his ability would allow. Moreover, parental attitudes toward work and toward education are powerful influences on the career development of all children. Career education programs for the handicapped must work to modify such attitudes through information and other experiences.

C. *Counseling and guidance profession*: The attention to the needs of special populations and particularly the area of the handicapped has been noted by the National Advisory Council on Vocational Education. In their sixth annual report (1975) they recommended that increased resources be made available to special populations: "Special populations are in need of improved quality and quantity of career guidance and counseling services." They also noted that employment service and vocational rehabilitation counselors are evaluated in terms of number of cases closed rather than quality of service provided, and they recommended that steps be taken to modify this practice.

The American Personnel and Guidance Association's Borad of Directors at its meeting in December 1974 adopted a position paper on career guidance and the role and functions of the guidance and personnel practitioner in relation to career education. The paper identified seven functions appropriate to the career guidance practitioner in behalf of furthering career education: serving as liaison between educational and community resource groups; conducting career guidance needs assessement surveys; organizing and operating part time and full time educational, occupational, and job placement programs; conducting followup, follow-through, and job adjustment activities; participating in curriculum revision; participating in efforts to involve the family in career education; monitoring and assessing professional activities; and communicating the results of these activities to other practitioners.

Barriers to Career Education of the Handicapped

Consideration must be given to some of the obstacles to career education that confront handicapped individuals. One obvious and pervasive problem is that of physical access to educational programs, training facilities, and employment areas.

Geography is an additional complication for some of the handicapped. In particular, the handicapped in rural areas frequently do not have opportunities for education, training, and/or employment. (This factor was noted in the Maryland study cited below.) One response to such a need is the development of residential services conjoint with day facilities (vocational schools, community colleges, etc.).

Another problem is that of insuring appropriate and adequate funding for programs of career education for the handicapped. In 1975 the Maryland Advisory Council on Vocational Technical Education conducted a study directed at the unmet needs for vocational training in that state, and one of the significant populations identified as needing training was the handicapped.

Maryland's findings are also borne out nationally. Although the Vocational Education Act of 1968 stipulated that at least 10% of Part B funds (Basic State Grant Programs) be allocated for the development and implementation of vocational education programs for handicapped individuals in each state, the 1974 report by the US General Accounting Office (analyzing funds through 1973) found the actual overall range varied from 8% to 17% with an average of 11%. There were 14 states, in fact, that had not met the minimum compliance requirements of 10%. Other available data similarly indicate that, while more money has been appropriated for vocational programs for handicapped, individuals, a significant number of handicapped individuals are not being served in vocational educational programs.

Development of Programs in Career Education

Despite the real and necessary participation of various societal elements in career education, the school is the most pervasive agency in shaping the future career directions for the handicapped individual. For too long the concept of most educational programs has been that the handicapped individual will fit and be fitted into jobs at the skilled and unskilled level; too few handicapped individuals have been assisted in

their own choices or in their own efforts to pursue higher education and/or go into a broad range of career choices. Task analyses involved in assessing career roles at all levels and relating them to the interests and capabilities of handicapped individuals is a critical need.

Although most special education school programs have been vocationally oriented, much of the recent support and impetus for career training has come from the Rehabilitation Service Administration and state Division of Vocational Rehabilitation (DVR) resources. In many states, DVR personnel have been energetic and relatively successful in exploiting community resources for the career training of handicapped individuals.

The development of programs in career education for students in special education programs and for students who wish to work with handicapped individuals should be encouraged, even though these programs have increased in number within the past 5 years. In 1973 The Council for Exceptional Children conducted a conference concerned with career education and handicappped students. One of its strong directions was the movement away from labeling and categorization and toward the mainstream concept. The conviction was stressed that as long as the handicapped individual was stereotyped, labeled, segregated, and treated separately in school that the broader society would continue to treat him similarly in employment, in higher education opportunities, and in other considerations. Also emphasized was the team approach—the necessity of a variety of disciplines assisting the child and the teacher in developing realistic self concept and career related attitudes and skills. This should be a lifelong process which impacts on adults at all stages of development.

As Talagan (1973) commented, "The process of using the community must be a sequential one where teachers explore from kindergarten up the possibilities of work contained in the community. We should no longer build curriculum in the 'ivory tower' of the university. We should build curriculum in the community where we ask people in business what they want, where we ask employers what they want, and where we ask the children what they want." Add to this data the information getting back into the career education programs from the labor force students. Only in this manner can career education be held accountable to its own graduates.

Exploring All the Possibilities

In summary, career education's goal is to make work possible, meaningful, and satisfying for all individuals. To achieve this for handicapped persons society must respect their right to choose from the widest possible set of opportunities. Until the total array of work possibilities for a handicapped citizen has been explored and made functionally possible, society is less than fair to the person and less than just to itself.

CONTINUING EDUCATION

Continuing education is the process by which an individual may at any age level enter into a training program to further his or her vocational or avocational goals.

The Need

Rapidly changing social conditions require early and appropriate adaptations of behavior. These adaptations depend heavily upon the acquisition of new knowledges and skills, many of which are not learned spontaneously by exceptional individuals. Consequently, a process of lifelong instruction is needed to equip post-school individuals in all age ranges and diability groups with the new responses that will determine a handicapped person's survival, let alone success, in our society. Currently, school programs for the exceptional generally terminate at age 21 or earlier despite the evident need for continuing education. In a few communities, nonschool agencies are making spasmodic attempts to provide lifelong education services to persons with certain disabilities, but such programs reach only a small minority of handicapped adolescents and adults. In view of this situation, millions of exceptional individuals are unable to sustain themselves adequately in the community at even the adaptations levels that they reached during the school years. Continuing education should be considered as one area of the need for comprehensive services for the handicapped individual. Comprehensive services will include total programs in the services of health, education, and welfare.

The Barriers

Some of the central barriers to continuing education for handicapped individuals are that:

1. Mandatory education often extends only to age 21 at the maximum.
2. The adult special education tradition is not strong in the United States.
3. Special education has traditionally addressed itself to younger individuals.
4. The possible content and procedures for continuing education for the handicapped have not been explicity described.
5. Suitable adult education service delivery systems have not yet been evolved for urban, suburban, and rural areas that overcome problems of transportation; limited physical, intellectual, emotional, and learning capacities; and stereotyped and irrelevant curricula.
6. Industry does not have adequate experience in modifying their training programs to accommodate handicapped individuals.

Types of Continuing Education

Differences among exceptional people create a need for a variety of adult education options, including:

1. Continuing career education and vocational training for employed persons who need to have their vocational skills upgraded to meet a changing labor market.
2. Leisure education to enable handicapped individuals to use their time constructively and pleasurably as the aging process modifies interests and capacities.
3. Health education to assist exceptional adolescents and adults to understand their changing disabilities more fully and to maximize their residual capacities through informed self care and efficient use of health resources.
4. Environmental awareness to enable the mentally retarded (as well as others) to better understand the changing demands of daily living and improved means of managing their lives as independently as possible within the context of social change.
5. Continuing educational experiences aimed at the identification and development of maximum potential.

Current Status of Programing

Rehabilitation agencies often provide continuing education targeted toward improved functioning levels. However, almost all of these programs (for example, in the area of daily living remedial education, and vocational training) are of relatively short duration and terminate either when the stipulated goals have been attained or the disable individual has benefited to the fullest degree possible from the program. Other than a small number of continuing education programs for the handicapped offered by local disability organizations, continuing education for the exceptional has been carried out in the framework of the local adult education mainstream, which has generally operated on a small scale. Some of the most effective programs have emerged in day centers for the retarded and other disability groups. These range widely in goals and quality, and efforts need to be made to enlarge the scope, programing, and comprehensiveness of these programs.

Restructuring Continuing Education for the Exceptional

Rusalem (1972) has suggested that a new conceptual context is needed for continuing education. The overarching concern should be a view of the exceptional individual as a developing person throughout the life span with almost limitless growth possibilities, which could be realized within the confines of an effective continuing education program. From this perspective, the needs are to:

1. Ascertain developmental potentials and goals for each handicapped adolescent and adult.
2. Maintain an exceptionally rich and resourceful continuing education program from which individualized program choices may be made.
3. Deliver long range counseling to the exceptional person to help him or her make the best use of these expanded resources.

Continuing Education Procedures

A variety of continuing education arrangements should be tried to ascertain the conditions under which each is suitable for various disability groups and individuals in those groups. Among the promising arrangements are (a) adult "colleges," (b) life span education and rehabilitation centers, (c) extension of existing special education programs to the postschool group, (d) adult home study and home instruction programs, (e) expansion of use of telecommunications in adult education, and (f) the development of educational self help groups in which

handicapped persons instruct other handicapped persons.

The Learning Dimension

Rusalem and Rusalem (1975) discovered in their Learning Capacities Research Project that a large majority of severely disabled adults have serious learning problems. Some of these problems are recognized in the school years, but despite all instructional efforts, they persist and often become exacerbated. Others were not fully recognized in the school years but now constitute important barriers to the intellectual and social growth of the disabled individual. A corps of specialists in adult and adolescent learning problems is needed to implement the techniques evolved by the Learning Capacities Research Project so that the instruction offered in continuing education for the exceptional can be keyed to the learning attributes of those served. Indeed, the limitations that many handicapped persons have in acquiring new skills and knowledges from the natural environment not only lead to impoverished lives but also to extreme dependence and institutionalization.

Potential Solutions

To avoid unnecessary dependence and institutionalization of the handicapped, action must be taken by those responsible for their education. Following are some steps which should be considered:

1. An adult and continuing education section could be developed in the Bureau of Education for the Handicapped with earmarked funds to support programs in this area.
2. A national continuing education center for the handicapped could be developed to assume leadership in creating and demonstrating innovative programs.
3. Local special education programs could be mandated to offer lifelong services.
4. Self-help educational programs could be organized and funded.
5. Learning capacities approaches could be incorporated into all educational activities for handicapped adolescents and adults.
6. Short term workshops or institutes could instill specialized skills in handicapped individuals.

PERSONNEL REQUIREMENTS FOR EDUCATION OF THE HANDICAPPED

Supply and Demand

About 130,000 special teachers of the handicapped are employed in the United States, mostly in service to children in the school age range (5 to 17 years old). It has been estimated (Balow, 1973) that about 240,000 more such teachers would be required just to serve all handicapped students of school age, thus giving a total needed figure of about 370,000. Many more would be required to provide full services to all children and youth. For example, an estimated 60,000 additional teachers would be required to serve the estimated 1 million preschool age handicapped children, and great but unmeasured needs exist to prepare teachers for secondary and postsecondary schools, particularly for vocational programs.

Preparation Centers

The role of colleges and universities as the only agencies authorized to offer credit for professional study is changing. In some places local school systems may assume the role of inservice trainers. Coordination must take place between higher education training institutions and local school systems for implementing the variety of training programs needed to supply personnel to train handicapped students.

The present state of employment and the preservice preparation of teachers of the handicapped represent a vast change in the past three decades. For example, in 1948 only 77 colleges were known to be providing a training sequence in even one category of special education; by 1954 the number was 122 (Mackie & Dunn, 1954); and now it is well over 400. Many of the colleges now involved in special education teacher preparation offer a variety of sequences, and thus there has been a large increase in training capacity. Much of the recent growth in preparation program reflects the burgeoning federal participation in the funding of programs through the Bureau of Education for the Handicapped.

Categories for Certification, Training, and Employment

Most states now offer certification to teachers (including speech clinicians) in about seven or

eight different categories of special education (see Abeson & Fleury, 1972). College training programs and employment opportunities have tended to follow the same categories. Those most frequent are as follows: educable mentally retarded, speech correction (therapy, clinicians, etc.), learning disabilities, emotionally disturbed, hearing impaired, visually impaired, orthopedically (and other health) impaired, and trainable mentally retarded.

There is some indication that the number of different kinds of certificates may be tending to diminish. The DELPHI survey conducted as part of The Professional Standards and Guidelines Project of The Council for Exceptional Children (Reynolds, 1973) showed that special education "leaders" expected the special education certification categories to come down from seven or eight to about four. That view was shared by state directors of special education and college faculty members. The survey was interpreted as showing "strong expressions for reducing the number of different kings of state certification."

Other parts of the survey showed that the most likely emerging pattern would be to hold firmly to special certification in three areas—speech correction, hearing impairments, and visual impairments—while collapsing across some of the other categories. This trend, if it crystallizes as anticipated, would not necessarily show lesser concern for specialized roles and specificity of competencies. Rather, it might show only that the degree of specificity in negotiations for certification between individuals and state departments of education would be reduced while negotiations with training centers and employers become all the more specific. Perhaps, however, such negotiations would be based more on "competencies" than on traditional categories.

Additionally, many other studies are tending to show a positive trend toward the development of more generic degrees in special education such as the combination of competencies in learning and emotional disabilities and mental retardation. Collasping of these specialities makes it possible for graduates to function adequately in a broader range of settings. The movement away from particular course offering to an emphasis on competencies is also reflected in places where standards for certification and accreditation are being formulated and refined (Reynolds, 1973). As more states adopt "right to education" statutes, the base of experience and approaches should provide a clearer picture of the most efficacious certification techniques.

The Distribution Problem and Potential Solutions

Special education services have always been maldistributed, but never so obviously as now when courts have directed that all children be served. One key facet of the distribution problem is that specialists tend not to go to certain high need areas for employment. For example, it is difficult to place highly trained teachers of Braille and of Mobility in rural areas where they would serve a small number of widely scattered visually handicapped children and where a major portion of their time would be spent in traveling. Somehow, better methods of recruitment, placement, and utilization of specialized personnel must be found so that the obligation to serve children in normal environments can be realized, even for those in remote and rural areas.

One possible solution may be for federal and state officials to organize a hierarchical system in which personnel needs are specified for whole states or broad regions; then the corresponding training functions could be allocated to institutions of higher education. Recruitment, training, and placement of trainees would be monitored and evaluated according to distribution needs, including the needs of rural areas. There are some signs of movement in that direction: programs of voluntary coordination by colleges and state department of education are encouraged and are reviewed by federal officers before training grants are awarded.

More funds need to be made available to local schools and agencies, thus permitting them to purchase training. It might be assumed that they would recruit, select, and provide support for training indigenous teacher candidates, those who are firmly committed to return with their specialized skills to the communities sponsoring them. Another probable effect would be to draw training resources of the colleges out to communities where they are needed for on the job training. This would force college departments of special education to package their programs and make them more "exportable."

Role Changes

Current forces and trends appear to be fostering some predictable role changes for special

education personnel. Listed below are some tentative observations and predictions about these role changes:

A. *Special education as a support system*: It appears to be the case now as well as a persisting trend that more special education teachers may go into what might be called support roles, that is, teaming up with regular teachers rather than operating laregly in separate classes, schools, and centers. Some of the implications of this change are that:

1. Special education personnel may be less identified with categories of exceptionality when working in support roles, However, support teachers are not a substitute for the highly trained and specialized teacher who must work with a homogeneous group of students, and these specialized classes will remain as part of the educational system.
2. Regular teachers will, both through formal training and work experience with special educators, become more knowledgeable and resourceful in dealing with exceptional pupils. This will require extraordinary investments of time and resources.
3. Special education personnel will be selected and prepared for more indirect influences in the schools, as in consultation and change agent roles.
4. Major restructuring will occur in the college training programs for special education personnel, becoming less categorized and more integral with general teacher preparation.

B. *More child study in schools*: It may be predicted that traditional methods of referring children to specialists for diagnosis will decline in practice, and instead, a diagnostic capacity will be built within individual school buildings. Some the the implications of such a change, will special reference to personnel roles, are that:

1. More dependence will be placed upon diagnosis by teams of regular school personnel, including school principals, special and regular teachers, and others who also carry responsibility for follow-through instruction—all of this in cooperation with parents.
2. More training will be provided for parents so that they can participate effectively in decision making and monitoring concerning the education of their children.
3. The "waiting time" for child study in special centers will hopefully disappear or be reduced.
4. More study of the child's school and total life situation as an adjunct to direct assessment of the child will occur.
5. Parents will be more involved in studying children and in making programmatic decisions.
6. Diagnostic functions will be more broadly integrated within the school into learning centers, which may also include instructional materials and the library.
7. Specialists such as psychologists will be used more in indirect roles as trainers and consultants to individual school based personnel.
8. Much less simple categorization of and prediction for children and more explicit orientation to the planning and evaluation of instruction will be encouraged.
9. More effects on total school atmosphere will be seen as programs for exceptional children are integrated.

C. *More local educational services for the severely and profoundly handicapped*: It is already the case that many severely handicapped children are being returned from institutions and hospitals to the community for education. The implications of this action are:

1. A rising demand for teachers prepared to deal with severely and profoundly handicapped students.
2. New demands for paraprofessionals who can serve in supportive roles in service to the severely handicapped.
3. Increasing attention to complex problems of diagnosis as in distinguishing problems of autism, retardation, and deafness.
4. More use of nontraditional personnel (such as psychologists) in instructional roles.
5. Closer coordination of school and home programs through parental consultation.

RESEARCH AND EDUCATION

This section of the paper attempts to review, briefly, the current status of support dissemination, and implementation of research on the education of the handicapped and then to identify both areas of research need as well as problem areas related to conducting research on the education of the handicapped.

Before discussing the current status of research and research needs, a few comments regarding the manner in which the term "research" is used here are relevant. Research is the process of asking questions and the seeking of answers to those questions in an objective, controlled, and repeatable manner. The objective of research is to allow the researcher to identify unequivocal relationships between manipulated variables and a performance measure of interest. Research is, by its nature, an intellectual enterprise. The development of useful products based on the outcomes of research should not be construed as research. Development uses facts established through research as a basis for manufacturing usable products. This distinction is made because of the increasing tendency to regard development as research rather than as a by-product of research-based knowledge.

Current Status

Research activity focused on the education of the handicapped has been vigorous for less than a decade. This is true in spite of the fact that public programs for the handicapped have existed since the turn of the century and have been prevalent since the middle of the century. While we have learned many things about teaching the handicapped during the past 10 years, we have also learned how little we actually know. Because research on the handicapped is in its infancy, it, obviously, requires more research.

In spite of the need for research in all areas of the handicapped person's development, not all areas receive the appropriate level of attention. Research needs and priorities vary from year to year more on the basis of complex sociopolitical factors than on any knowledge base. This fact leads to a focus on politically relevant rather than scientifically relevant topics for study.

A recent study (Kakalik, Brewer, Dougharty, Fleischauer, & Genensky, 1973) esimated that state and federal governments spend $4.73 billion annually for services to the handicapped. Of this sum only $120 million is spent on research. This means that only 2% of the annual expenditures on behalf of handicapped persons is spent to obtain knowledge on the provision of the services purchased. The majority of funds spent on research related to the handicapped are those from the National Institutes of Health. Research on the education of the handicapped is estimated at $10.79 million annually (Glickman, 1975), which is less than 9% of all the research funds expended on the handicapped.

The Bureau of Education for the Handicapped supports almost all educational research on the handicapped. During the 1975 fiscal year that support was divided as follows: approximately 47% was directed to noncategorical research, 25% was spent in the area of mental retardation, 8% each was used for the visually and hearing handicapped with the remaining 12% spread across the crippled and health impaired, emotionally disturbed, and speech handicapped. The Bureau's priority areas for the distribution of funds were as follows: full school services (48%); child advocacy, career education, and personnel development (13% each); severely handicapped (7%); early childhood education (5%); and combined objectives (1%). While it is difficult to determine precisely, many of these research funds were supporting development rather than research activities.

An additional characteristic of the current status of research on the education of handicapped individuals deserves mention. No *detailed* explication of the research needs in the area of the handicapped person is currently available. There are also no coordinated research plans designed to meet the educational needs of handicapped persons.

Research Needs

A. *Interdisciplinary research results*: A major need is the interpretation and dissemination of the research results from the disciplines of medicine, biology, and genetics. There have been marked advances in the identification of causes of handicapping conditions. These data must be made accessible to teachers, community agencies, and the public at large.

B. *Systems for evaluation*: The process of evaluating the cognitive, motor, self-help, and personal and social skills of handicapped individuals has two objectives: classification and program development. A wide range of tools has been developed for classification. Unfortunately, many of these tools do not lend themselves to effective educational programing. Furthermore, as noted by Hobbs (1975), these tools do not result in cross catetgorical systems for classifying handicapped individuals. Hobbs pointed to the critical need for the development of a comprehensive, cross categorical system for diagnosing and classifying. The intent of the system would

be to provide program planners with educationally relevant information about each student. Given this intent, it should be possible to develop a system that would be useful for classification purposes and that would also provide precise educational plans for each handicapped person classified.

C. *Learning characteristics and strategies*: Educational programs for handicapped children, youth, and adults assume that the instructor has a general understanding of the learning processes of the persons with whom he or she is working. Practitioners, however, frequently express dissatisfaction with their level of understanding regarding their students' learning skills. This fact is not surprising given the lack of empirically based descriptions of the learning performances. In Gallagher's (1975) recent review of child development research and exceptional children, research needs within each category of exceptionality were identified. The most frequently identified research need was to identify and understand the basic learning processes and strategies by which the handicapped process information.

D. *Longitudinal research*: The Gallagher (1975) review identified longitudinal research as an important need. Such research should focus on:

1. The cognitive and personal and social development of the handicapped, particularly as it influences the development of competence.
2. The relationship between family variables and the personal and social adjustment of the handicapped.
3. The relationship between developmental characteristics, habilitation programs, and the adult status of the handicapped. A desperate need for information regarding the long term nature and quality of life of the adult handicapped exists.

In addition to these general topical areas of research need, there are research problems in need of solution. First, there needs to be a better balance in resource distribution. The imbalance between biomedical and educational research funding should be corrected. Support for basic and applied research should be equalized, and there should be a better balance of support between categories of handicap and priority areas.

A second need is for better research dissemination. The only comprehensive system for disseminating the results of research and development efforts is the ERIC Document Reproduction Service. Additional mechanisms other than journal publications are needed for the rapid and widespread distribution of the results of significant research.

Finally, there is a need for better research training for both practitioners and researchers. Practitioners need to be trained in how to interpret the results of research, apply the results of research to their program, and use research techniques to make data based decisions regarding their day to day activities. Researchers need to be better trained in identifying researchable questions, designing experimentally valid research, and presenting the results of their research in understandable language and usable formats. Practitioners can also be trained to work with researchers in identifying research questions of a programmatic nature and implementing projects that could have impact on practice. Funding sources also need to be able to make commitments to diverse types of research programs.

PUBLIC INFORMATION AND EDUCATION

The Growth of Public Awareness

As the records from our early beginnings show, educational programs for the handicapped prior to 1900 were conducted in residential settings. The new century brought public awareness in general and parent pressures specifically. By the 1920's, two-thirds of the large cities had special classes.

While communities continued to establish programs, the real growth of special education came at the close of World War II. A number of young men who had left home physically fit and respected in their home communities returned as blind and physically handicapped veterans. Having established a place in society prior to the onset of their handicap, they were able to reestablish themselves in the community and aid in bringing about a change in attitude regarding handicapped persons. In addition to wounded veterans, the increasing public awareness of the results of automobile and home accidents created a sensitivity to the special needs of persons disabled later in life.

This new awareness created a moral responsibility for providing opportunities for handicapped children to receive a public school

education. As more classes for the blind, deaf, and physically handicapped were established, parents of retarded children joined to form a parents' lobby to provide greater availability of educational programs for the mentally retarded. Although a number of states have now mandated special education classes for all handicapped children, and although Public Law 94-142 mandates educational awareness campaigns in each state, much yet remains to be done.

Early intervention and the current emphases on placement of handicapped students in the least restrictive environment and on family involvement in the educational process make awareness and information about successful programing imperative. The process of identifying and enrolling handicapped children in special education programs is contingent on the awareness and attitudes of parents of these handicapped children. Also, potential employers need to be educated about how handicapped people can be placed into meaningful employment circumstances, given selective job placement strategies. Handicapped people have repeatedly reported that the disability itself does not create as much of a handicap as the negative attitudes other people have toward it. Usually the attitudes can be traced to lack of information, misunderstanding, or apprehension concerning how to deal with handicapped people.

Education for Prevention

Continued efforts need to be made to inform the public at large that many handicapping conditions occur before birth and can be prevented. Also, not all handicapped persons are born handicapped but many become so as a result of accidents, toxic substances, and diseases. Many of these conditions can be avoided through inoculations and simple safety precautions. Constant attention must be paid by industry to the development of safe products and safe working conditions for all humans. The efforts of the National Safety Council should be made readily available.

Present Media Efforts

Local radio and television stations and newspapers provide an excellent opportunity to tell the special education story. One notes the continual growth of the media's attention to handicapped children and adults. In the past, handicapped children have not often been pictured in books or seen on television. Recently, however, *Sesame Street, Mister Roger's Neighborhood*, and *Captain Kangaroo* have included children with handicaps.

Although the media appears most receptive to its role in public information and education, those concerned with the education story must recognize some present limitations and take measures to overcome them. Daily papers are primarily interested in news. If the news can report a unique new program, a funding source, a new screening device, or items with budgetary implications, they may be included. The Sunday feature may occasionally be devoted to information about the handicapped, and such features often will present a human interest story with rosy overtones and happy endings.

Weekly papers will use items eventually if copy is provided. Most newspapers do not have sufficient staff to generate this kind of copy. At the present time it has been found that small newspaper chains are frequently educationally oriented and that local weekly papers are good information disseminators. It would appear that the most successful programs for awareness and understanding of educational programs are those being conducted on the local level but unfortunately in a fragmented and splintered way.

Increasing the Efforts

Successful educational programing for the handicapped can no longer be perceived as a self-contained class established to provide for those children who have been unable to cope in regular classes and who will remain dependent after they have finished school. Availability of early identification, diagnosis, specialized programing and services, career awareness, and postsecondary training are all equally important components. Parents need to recognize problems and know where to seek help. Service agencies, both public and private, must be aware of each other's existence and know how to coordinate services. The medical profession must be aware of and understand the philosophy of special education programing, as must regular classroom teachers and school administrators, who will be involved in placing the handicapped in integrated environments. The general tax paying public must know about differential costs for

education handicapped persons, and the necessity to support programs of specialized education. They must realize that such costs are investments—human investments that profit society.

It has been suggested that generally the use of media has been more concerned with the publicity than public relations. One brief radio or television spot fails to tell the total message. Educating the media must become a responsibility of educators, handicapped persons, and parents alike. The National Advertising Council has supported the President's physical fitness program and health related programs in a comprehensive organized way, which tends to make an impact. If useful information and a basic understanding about the handicapped are to be presented in a sequential meaningful fashion to appropriate audiences, such information must be generated and disseminated in a systematic way.

SUMMARY

Although the democratic premise that education is the right of all, throughout the history of American education handicapped individuals have faced a policy of exclusion rather than inclusion. It is estimated that in the United States there are 7 million (plus 1 million of preschool age) handicapped children, who because of their handicaps require special education programs. Only about 40% are receiving the kind of educational program necessary to achieve their maximum capacity.

This paper addressed the topic areas of (a) legal right to education, (b) finance, (c) delivery systems, (d) early childhood education, (e) severely handicapped, (f) career education, (g) continuing education, (h) personnel requirements, (i) research, and (j) public information and education. Throughout the paper the involvement of parents and family was discussed. The potential impact of the Education for All Handicapped Children Act, Public Law 940142, was also noted in the various topic areas. Clearly, the implementation of the right to education mandate, and the monitoring of the actions of the schools, are primary issues before the consumer and professional communities. Key concepts discussed in the paper include the following:

1. Vigorous and imaginative actions of consumers and professionals have been the force behind the now *legally* established right that handicapped school age children have the same rights as nonhandicapped students to a free, public, and equal educational opportunity. Implementation and monitoring of the schools require the cooperation of parents, advocacy groups, and professionals.

2. At a time when education budgets are being reduced or contained, the public needs to understand the costs related to a total "inclusion" program of handicapped persons in education. Understanding must, in turn, breed support.

3. A delivery system is the programmatic way of providing an educational program. "Mainstreaming" is the current approach but would be more meaningful if defined in the terms of the "least restrictive environment." Such a delivery system focuses on a full continuum range of placement, heavily involves parents in decision making, and requires an array of ancillary services.

4. A recent national movement in the education of the handicapped is early childhood education. The importance of early education is stressed. Early stimulation of children and special programs reduce the number of children who will need intensive or long-term help and will enable many who before were in special class placements to enroll and function satisfactorily in the regular school classroom. Family participation is essential, but a range of supporting and respite services is also needed. Presently only 25% of the preschool handicapped are receiving the appropriate, specialized services they need.

5. The management of severely handicapped persons has just recently become an educational rather than a custodial concern. Public Law 94-142 provides the opportunity for the country's severely handicapped to achieve full realization of their right to an education—a right traditionally denied rather than granted. Essential elements to a total program include: starting intervention at birth; intensively involving various disciplines, in addition to the teacher, in the classroom program; planning if necessary for lifelong attention; establishing programs to train educators for new, needed skills; and providing support and training to parents from the moment the severely handicapped child is identified. An underlying factor is the necessity for a basic change in community attitudes—to reverse old attitudes and to open the community to handicapped persons.

6. Career education must span the entire life cycle since "career" and "education" span preschool through retirement. The current predictions of unemployment, underemployment, poverty level employment, total dependence, and institutionalization for handicapped persons leaving the school systems are more than a concern, and they may serve as a real indictment to education and society unless aborted. Handicapped individuals should be able to make decisions on their own career choice and education. Agencies other than education, such as those of business, labor, and the community, need to make their contributions to a total career program for the handicapped.

7. A new conceptual context is needed in the continuing education for the handicapped—a context that will replace the current orientation of recreation, busywork, and health with a focus on the individual as a developing person throughout the life span. Handicapped persons must be viewed as having almost limitless growth possibilities, which could be realized within an effective continuing education program. Delivery systems have not yet been created that overcome problems of transportation and limited physical, intellectual, emotional, and learning capacities. A variety of continuing education arrangements, such as adult "colleges," life span education centers, adult home instruction programs, should be tried.

8. The need for adequate numbers of trained personnel continues. Special education services have always been maldistributed, but now with the court mandate to serve all children the situation becomes more critical. Solutions may be in the mapping of broad geographical regions and allocating corresponding training functions to certain higher institutions of education and/or shifting some college training funds to local schools and agencies permitting them to purchase training. The latter assumes that they would recruit and train personnel who would be firmly committed to return with their skills to the sponsoring communities.

9. It is possible to identify an almost limitless number of research needs in the area of the education of the handicapped. Research related to (a) better evaluation/classification systems, (b) understanding the learning strategies of the handicapped, and (c) long-term, longitudinal studies were identified as three significant areas of research need. Three logistic support related problems were also identified and discussed: better balance in resource distribution, better research dissemination, and better research training for both practitioners and researchers.

10. New programs in early intervention, placement of handicapped students in the least restrictive environment, programs for the severely and profoundly handicapped, and family involvement in the educational process make awareness and information about successful programming imperative.

A total partnership of federal, state, and local education agencies, along with the consumer and professional community, can reverse the inadequacies of the past and make the goal of education for all a reality.

REFERENCES

Abeson, A., & Fleury, J. B. (Eds.). *State certification requirements for education of the handicapped.* Arlington VA: State-Federal Information Clearinghouse for Exceptional Children, The Council for Exceptional Children, 1972.

Allen, K. E. *Early education for all young children.* Paper presented at OCD/BEH Outreach Conference: Give the Handicapped a Head Start, Arlington VA, September 1975.

Allen, K. E., Holm, V. A., & Schiefelbush, R. L. *Early intervention—A team approach.* Baltimore: University Park Press, in press.

American Personnel and Guidance Association. *Career guidance: Role and functions of counseling and personnel practitioners in career education.* Position paper adopted at the APGA Board of Directors meeting, December 12-14, 1974.

Balow, B. B. Statement before the Subcommittee on Handicapped of the Committee on Labor and Public Welfare, US Senate. *Hearings* for March 20, 21, and 23. Washington DC: US Government Printing Office, 1973.

Barone, C.S. Paper presented at Forum of National Organizations sponsored by Vocational Evaluation and Work Adjustment Association, the National Rehabilitation Association, and the Presient's Committee on the Employment of the Handicapped, October 25, 1973.

Bellamy, G. T., Peterson, L., & Clse, D. Habilitation of the severely and profoundly retarded:

Illustrations of competence. *Education and Training of the Mentally Retarded,* 1975, *10,* 174-186.

Bernstein, C. D., Kirst, M. W., Hartman, W. T., & Marshall, R. S. *Financing educational services for the handicapped: An analysis of current research and practices.* Reston VA: The Council for Exceptional Children, 1976.

Bertness, H. J. Progressive inclusion: One approach to mainstreaming. In J. B. Jordan (Ed.), *Teacher, please don't close the door: The exceptional child in the mainstream.* Reston VA: The Council for Exceptional Children, 1976.

Bolick, N. (Ed.). *Digest of state and federal laws: Education of handicapped children* (3rd ed.). Reston VA: The Council for Exceptional Children, 1975.

Bricker, D. Educational synthesizer. In M. A. Thomas (Ed.), *Hey, don't forget about me* (Report on the Invisible College on the Severely, Profoundly, and Multiply Handicapped, San Antonio TX, January 1976). Reston VA: The Council for Exceptional Children, 1976, in press.

Bureau of the Census. *Current population reports consumer income: Characteristics of population below poverty level, 1974.* Series P60, No. 102, January 1976.

Caster, J. What is "mainstreaming"? *Exceptional Children,* 1975, *42,* 174.

Child find. Proceedings from the Child Find Conference sponsored by National Coordinating Office for Regional Resource Centers, University of Kentucky, Lexington; and National Association of State Directors of Special Education, Washington, DC, March 26-27, 1975.

Connor, F. P. Some issues in professional preparation—Education of the severely handicapped. *Educating the 24-hour retarded child.* Paper presented at conference on education of severely and profoundly retarded students, National Association for Retarded Citizens, New Orleans LA, March 1975.

Cratty, B. J. *Perceptual and motor development in infants and children.* New York: The Macmillan Company, 1970.

DeWeerd, J. Introduction. In J. B. Jordan (Ed.), *Early childhood education for exceptional children—A handbook of ideas and exemplary practices.* Reston VA: The Council for Exceptional Children, 1976, in press.

Dmitriev, V. Motor and cognitive development in early education. In N. G. Haring (Ed.), *Behavior of exceptional children—An introduction to special education.* Columbus OH: Charles E. Merrill, 1974.

Dobbing, J. Human brain development and its vulnerability. In *Biologic and clinical aspects of brain development* (Proceedings of the Mead Johnson Symposium on Perinatal and Developmental Medicine No. 6). Evansville IN: Mead Johnson & Co., 1975.

Gallagher, J. J. (Ed.). *The application of child development research to exceptional children.* Reston VA: The Council for Exceptional Children, 1975.

Glickman, L. J. Research activities for handicapped children. *American Education,* 1975, *11* (8), 30-31.

Gold, B. Personal communication, 1975.

Gold, M. W. Stimulus factors in skill training of retarded adolescents on a complex assembly task: Acquisition, transfer, and retention. *American Journal of Mental Deficiency,* 1972, *76,* 517-526.

Gold, M. W. Vocational training. In J. Wortis (Ed.), *Mental retardation and developmental disabilities: An annual review* (Vol. 7). New York: Brunner/Mazel, 1975.

Harbin, G., & Cross, L. *Early childhood curriculum materials: An annotated bibliography.* (Tadscript #7). Chapel Hill: Technical Assistance Development System, The University of North Carolina, 1975.

Haring, N. Assessment and diagnosis of severely handicapping conditions. In M. A. Thomas (Ed.), *Hey, don't forget about me* (Report on the Invisible College on the Severely, Profoundly, and Multiply Handicapped, San Antonio TX, January 1976). Reston VA: The Council for Exceptional Children, 1976, in press.

Hart, V. *Beginning with the handicapped.* Springfield IL: Charles C Thomas, 1974.

Hobbs, N. *The futures of children: Categories, labels and their consequences* (Report of the Project on Classification of Exceptional Children). San Francisco: Jossey-Bass, 1975.

Horowitz, F. D., & Paden, L. Y. The effectiveness of environmental intervention programs. In B. M. Caldwell & H. N. Riccuiti (Eds.), *Review of child development research, Vol. 3: Child development and social policy.* Chicago: University of Chicago Press, 1973.

Hoyt, K. B., Evans, R. N., Mackin, E. F., & Margum, G. L. *Career education: What it is*

and how to do it (2nd ed.). Salt Lake City: Olympus, 1974.

Jones, P. R., & Wilkerson, W. R. *Options for financing special education.* Paper presented at the 17th National Institute of Educational Finance, Miami FL, March 1974.

Kakalik, J. S., Brewer, G. D., Dougharty, L. A., Fleischauer, P. D., & Genensky, S. M. *Services for handicapped youth: A program overview.* Santa Monica CA: Rand, 1973.

Karnes, M. B. Implications of research with disadvantaged children for early intervention with the handicapped. In J. B. Jordan & R. F. Dailey (Eds.), *Not all little wagons are red: The exceptional child's early years.* Arlington VA: The Council for Exceptional Children, 1973.

Karnes, M. B., & Zehrbach, R. R. Alternative models for delivering services to young handicapped children. In J. B. Jordan (Ed.), *Early childhood education for exceptional children—A handbook of ideas and exemplary practices.* Reston VA: The Council for Exceptional Children, 1976, in press.

Mackie, R. P., & Dunn, L. M. *College and university programs for the preparation of teachers of exceptional children* (US Office of Education, Bulletin 1954, No. 13). Washington DC: US Government Printing Office, 1954.

Marinelli, J. J. Financing the education of exceptional children. In F. J. Weintraub, A. Abeson, J. Ballard, & M. L. LaVor (Eds.), *Public policy and the education of exceptional children.* Reston VA: The Council for Exceptional Children, 1976.

Marland, S. *Marland and career education.* Washington DC: US Department of Health, Education, and Welfare, 1971. (Reprinted from *American Education*, November 1971.)

Maryland Advisory Council on Vocational-Technical Education. *Study of residential vocational technical centers in Maryland.* Annapolis MD: MACVTE, 1975.

McLure, W. P., Burnham, R. A., & Henderson, R. A. *Special education needs—Costs—Methods of financing.* Urbana-Champaign: University of Illinois, College of Education, Bureau of Educational Research, 1975.

Mithaug, D. In N. G. Haring (Project Director), *A second year progress report to the Bureau of Education for the Handicapped: The Center for the Severely Handicapped and the Child Development and Mental Retardation Center.* Seattle WA: University of Washington, Experimental Education Unit, 1976, in press.

Moore, C. (Ed.). *Preschool programs for handicapped children—A guidebook for the development and operation of programs.* Eugene OR: University of Oregon, Regional Resource Center for Handicapped Children, undated.

Myers, D. G., Sinco, M. E., & Stalma, E. S. *The right-to-education child: A curriculum for profoundly mentally retarded.* Springfield IL: Charles C Thomas, 1973.

National Advisory Council on Vocational Education. *Sixth annual report.* Washington DC: NACVE, 1975.

Partridge, D. L. A comprehensive special education program requires a firm foundation and structured support. In J. B. Jordan (Ed.), *Teacher, please don't close the door: The exceptional child in the mainstream.* Reston VA: The Council for Exceptional Children, 1973.

Reynolds, M. C. *DELPHI suvey—A report of rounds I and II* (Conducted for the Professional Standards and Guidelines Project of CEC). Reston VA: The Council for Exceptional Children, 1973.

Rusalem, H. *Coping with the unseen environment: An introduction to the rehabilitation of blind persons.* New York: Teachers College Press, 1972.

Rusalem, H., & Rusalem, H. *The learning capacities approach.* Paper presented at the Annual Conference of the National Rehabilitation Association, Cincinnati, 1975.

Schattner, R. *An early childhood curriculum for multiply handicapped children.* New York: The John Day Company, 1971.

Shearer, D. E. *Portage guide to early education.* Portage WI: Cooperative Educational Service Agency #12, 1972.

Shearer, M. S., & Shearer, D. E. Parent involvement for the handicapped. In J. B. Jordan (Ed.), *Early childhood education for exceptional children—A handbook of ideas and exemplary practices.* Reston VA: The Council for Exceptional Children, 1976, in press.

Sherr, R. D. The benefits, problems and proposed solutions for public school programs for the severely and profoundly handicapped. In M. A. Thomas (Ed.), *Hey, don't forget about me* (Report on the Invisible College on the Severely, Profoundly, and Multiply Handicapped, San Antonio TX, January 1976).

Reston VA: The Council for Exceptional Children, 1976, in press.
Sontag, E. The severely handicapped child in the public school—What we have to do! *Educating the 24-hour retarded child*. Paper presented at conference on education of severely and profoundly retarded students, National Association for Retarded Citizens, New Orleans LA, March 1975.
Sullivan, R. C. The future role of the parent. In M. A. Thomas (Ed.), *Hey, don't forget about me* (Report on the Invisible College on the Severely, Profoundly, and Multiply Handicapped, San Antonio TX, January 1976). Reston VA: The Council for Exceptional Children, 1976, in press.
Talagan, D. P. With career education we can individualize curriculum for children. *Exceptional Children*, 1973, *39*, 666.
Thomas, M. A. Finance: Without which there is no special education. *Exceptional Children*, 1973, *39*, 475-480. (a)
Thomas, M. A. *Extent of services provided for exceptional children and fiscal capacity of states*. Unpublished doctoral dissertation, Indiana University, Bloomington, 1973. (b) (Available from Xerox University Microfilms, Ann Arbor MI, CAT. No. 74-27-12.)
Trudeau, E. (Ed.). *Digest of state and federal laws: Education of handicapped children* (2nd ed.). Arlington VA: The Council for Exceptional Children, 1972.
US Government Accounting Office. *What is the role of federal assistance for vocational education?* Report to Congress and Office of Education, Department of Health, Education, and Welfare, Washington DC, December 31, 1974.
Weintraub, F. J., Abeson, A. R., & Braddock, D. L. *State law and education of handicapped children: Issues and recommendations*. Reston VA: The Council for Exceptional Children, 1975.
Werner, E. E. et al. *The children of Kaua I.* Honolulu: University of Hawaii Press, 1971.
Wilken, W., & Callahan, J. *State special education finance in the 1970's*. Draft document presented before the National Association of State Directors of Special Education, Reno NV, October 1975.
Yates, J. R. *Special education finance: Problems, issues, solutions, questions*. Presented at the Special Education Finance Conference, Chicago IL, 1975.

SUGGESTED ADDITIONAL READINGS

Abeson, A., Bolick, N., & Hass, J. *A primer on due process—Education decisions for handicapped children*. Reston VA: The Council for Exceptional Children, 1975.
Deno, E. N. (Ed.). *Instructional alternatives for exceptional children*. Arlington VA: The Council for Exceptional Children, 1973.
Lake, T. P. (Ed.). *Career education: Exemplary programs for the handicapped*. Arlington VA: The Council for Exceptional Children, 1974.
Reynolds, M. C. (Ed.). *Mainstreaming: Origins and implications*. Reston VA: The Council for Exceptional Children, 1976.
The Council for Exceptional Children. *Basic commitments and responsibilities to exceptional children and policy statement on governmental affairs*. Arlington VA: CEC, 1972.
Weintraub, F. J., Abeson, A., Ballard, J., & LaVor, M. L. (Eds.). *Public policy and the education of exceptional children*. Reston VA: The Council for Exceptional Children, 1976.

APPENDIX A

THE EDUCATION FOR ALL HANDICAPPED CHILDREN ACT PUBLIC LAW 94-142

On November 28, the President signed into law S.6, the "Education for All Handicapped Children Act." The President's approval followed overwhelming endorsement of the House-Senate conference agreement in the Congress, with the House giving its approval to the Conference report on November 18 by a vote of 404 to 7. On the following day the Senate gave its approval by a margin of 87 to 7. What follows is a characterization of the major features of what is now P.L. 94-142.

Formula

P.L. 94-142 establishes a formula in which the Federal government makes a commitment to pay a gradually-escalating percentage of the National average expenditure per public school child times the number of handicapped children

being served in the school districts of each State in the Nation. That percentage will escalate on a yearly basis until 1982 when it will become a permanent 40 percent for that year and all subsequent years.

Formula Scale

Fiscal 1978 ..... five percent
Fiscal 1979 ..... ten percent
Fiscal 1980 ..... twenty percent
Fiscal 1981 ..... thirty percent
Fiscal 1982 ..... forty percent

It should be carefully noted that such a formula carries an inflation factor, i.e. the actual money figure fluctuates with inflationary-deflationary adjustments in the National average per pupil expenditure.

Formula "Kick-In"

As obviously indicated in the preceding heading, the new formula will not go into operation until fiscal 1978.

It will be recalled that previously existing law was already moving toward a permanent, significant increase in the Federal commitment. Public Law 93-380, the Education Amendments of 1974 (signed August 21 of 1974), created the first entitlement for handicapped children, based upon factors of the number of *all* children aged three to twenty-one within each State times $8.75. This formula (called the "Mathias formula" after its originator), amounting to a total annual authorization of $680 million, was authorized for fiscal 1975 only—with a view toward permitting an emergency infusion of money into the States while at the same time deferring to final determination of a permanent new funding formula as now contained in Public Law 94-142. This "Mathias formula" would be retained in both bills until "kick-in" of the new formula.

Ceilings

For the two years of fiscal 1976 and 1977 when the formula remains under the "Mathias entitlement," the conferees set authorization ceilings of $100 million for fiscal 1976 and $299 million for fiscal 1977. On the basis of the current National average per pupil expenditure, the following authorization ceilings are generated for the first years of the new formula:

Fiscal 1978 ..... $387 million
(on the five-percent factor)
Fiscal 1979 ..... $775 million
(on the ten-percent factor)
Fiscal 1980 ..... $1.2 billion
(on the twenty-percent factor)
Fiscal 1981 ..... $2.32 billion
(on the thirty-percent factor)
Fiscal 1982 ..... $3.16 billion
(on the forty-percent factor)

Counting Limitation

P.L. 94-142 addresses the potential threat of "over-counting" children as handicapped in order to generate the largest possible Federal allocation. The measure prohibits counting more than 12 percent as handicapped served within the total school-age population of the State between the ages of five and seventeen.

Learning Disabilities

P.L. 94-142 retains, with minor alterations, the existing Federal definition of handicapped children (EHA, Section 602 (I) and (15) of extant law), and this definition includes children with specific learning disabilites. However, it would appear at this point of interpretation of conference action that the Commissioner may, within one year, provide detailed regulations relative to SLD, including the development of a more precise defintion, the prescription of comprehensive diagnostic criteria and procedures, and the prescription of procedures for monitoring of said regulations by the Commissioner. If the authorizing committees of the House and Senate disapprove the Commissioner's regulations, then a ceiling on the number of children with learning disabilities who may be counted by the State for purposes of the formula will be included when the new formula takes effect. The ceiling would provide that not more than one-sixth of the 12 percent of school-age children aged five to seventeen who may be counted as handicapped children served may be children with specific learning disabilities.

Priorities

Previously existing law (P.L. 93-380), in conformance with the overall goal of ending exclusion, orders a priority in the use of Federal funds for children "still unserved." P.L. 94-142

maintains and broadens that priority in the following manner:

* First priority to children "unserved"
* Second priority to children inadequately served when they are severely handicapped (within each disability).

This priority must be adhered to by both the State education agency and its local education agencies.

Beneficiaries

P.L. 94-142 stipulates that all handicapped children, aged three to twenty-one years, may enjoy the special education and related services provided through this measure. There is also provision for the use of Federal monies for programs of early identification and screening.

Pass-Through

As finalized, P.L. 94-142 contains a substantial pass-through to the local school districts. In the first year of the new formula, 50 percent of the monies going to each State would be allocated to the State education agency, and 50 percent would be allocated to the local education agencies. In the following year, fiscal 1979, the LEA entitlement would be enlarged to 75 percent of the total allocation to a given State, with the SEA retaining 25 percent. This 75-25 arrangement commencing in fiscal '79 becomes the permanent distribution arrangement. The current State-control of all funds is retained for the remainder of fiscal 1976 and fiscal 1977.

Constraints Upon Localities

Though P.L. 94-142 authorizes a substantial local entitlement, there are numerous "strings attached." Initially, the State education agency will act as the clearinghouse of all data from the localities gathered in order to determine local entitlement, and the State will transmit that information to the Commissioner. Furthermore, the State education agency may refuse to pass-through Federal monies generated when:

- the school district does not conform to the overall State-plan requirements contained in this Act and in existing law (such as "full service" goal, confidentiality, etc.);
- the school district fails to meet the local application requirements;
- the State deems the local district unable to make effective use of its entitlement unless it consolidates its entitlement with the entitlement of one or more other school districts (this apparently allows great flexibility in funding arrangements—intermediate districts, special districts, etc.);
- when the program for handicapped children within the school district is of insufficient size and scope;
- when the school district is maintaining "full service" for all its handicapped children with State and local funds. (This provision will end when all districts within the State have reached "full service," at which time a degree of supplanting will in effect be permitted.)

Most significantly, P.L. 94-142 sets a flat monetary minimum. If a school district, after counting all of its handicapped children served, cannot generate an allocation for itself of at least $7,500, a pass-through to that school district does not occur. This provision is, of course, also aimed at encouraging various sorts of special education consortia in order to make a meaningful use of the Federal dollars.

If an SEA withholds a local entitlement under any of the aforementioned circumstances, it must nonetheless assure that the monies generated by said entitlement are used to assure the public education of the handicapped children residing in the district in question.

State and Local Requirements

P.L. 94-142 makes a number of critical stipulations which must be adhered to by *both* the State and its localities. These stipulations include:

- assurance of extensive child identification procedures;
- assurance of "full service" goal and detailed timetable;
- a guarantee of complete due process procedures;
- the assurance of regular parent or guardian consultation;
- maintenance of programs and procedures for comprehensive personnel development including in-service training;

- assurance of special education being provided to all handicapped children in the "least restrictive" environment;
- assurance of nondiscriminatory testing and evaluation;
- a guarantee of policies and procedures to protect the confidentiality of data and information;
- assurance of the maintenance of an individualized program for all handicapped children;
- assurance of an effective policy guaranteeing the right of all handicapped children to a free, appropriate public education, *at no cost* to parents or guardian;
- assurance of a surrogate to act for any child when parents or guardians are either unknown or unavailable, or when said child is a legal ward of the state.

It is most important to observe that an official, written document containing all of these assurances is now required (in the form of an application) of *every* school district receiving its Federal entitlement under P.L. 94-142.

Hold Harmless

P.L. 94-142 stipulates that every State will be "held harmless" at its actual allocation for fiscal 1977 (the last year of appropriations under the "Mathias formula").

Excess Cost

P.L. 94-142 provides that Federal monies must be spent only for those "excess cost" factors attendant to the higher costs of educating handicapped children. A given school district must determine its average annual per pupil expenditure for all children being served, and then apply the Federal dollars only to those additional cost factors for handicapped children beyond the average annual per pupil expenditure. Such a requirement does not obtain for the State education agency in the utilization of its allocation under this Act. However, the State education agency is required to match its allocation on a "program basis," but is not required to match with new monies.

Individualized Instruction

P.L. 94-142 requires the development of an individualized written education program for each and every handicapped child served within a given state to be designed initially in consultation with parents or guardian, and to be reviewed and revised as necessary, but at least annually. This provision takes effect in the first year under the new formula, fiscal 1978. At least the following premises governed inclusion of this requirement:

- Each child requires an educational blueprint custom-tailored to achieve his/her maximum potential.
- All principles in the child's educational environment, including the child, should have the opportunity for input in the development of an individualized program of instruction.
- Individualization means specifics and timetables for those specifics, and the need for periodic review of those specifics—all of which produces greatly enhanced fiscal and educational accountability.

Date Certain

It is generally agreed that the Congress ought to fix a chronological date, however innately arbitrary, beyond which no State or locality may be failing without penalty to guarantee against outright exclusion from the public educational systems. Also, it is felt that the States ought to be given a reasonable, but not lengthy, time period in which to reach "full service."

P.L. 94-142 therefore requires that every State and its localities, if they are to continue to receive funds under this Act, must be affording a free public education for all handicapped children aged three to eighteen by the beginning of the school year (September 1) in 1978, and further orders the availability of such education to all children aged three to twenty-one by September 1, 1980. However, these mandates carry a big "if" in the area of preschool, apparently in the age range of three to five. Under P.L. 94-142 such mandate for children in that group would apply only when such a requirement is not "inconsistent" with State law or practice, or any court decree.

These date-certain assurances must be met as a matter of State eligiblity for funding under the Act, (Section 612).

Due Process

The vital provisions of previously existing law (P.L. 93-380, the Stafford guarantees") toward

the guarantee of due process rights with respect to the identification, evaluation, and educational placement of all handicapped children within each State are constructively refined in P.L. 94-142 toward at least the following objectives:

- to strengthen the rights of all involved;
- to conform more precisely to court decrees;
- to clarify certain aspects of existing law;
- to guarantee the rights of all parties relative to potential court review;
- to ensure maximum flexibility in order to conform to the varying due process procedures among the States.

It should be observed that these refinements take effect in the first year under the new formula, i.e. fiscal 1978. In the meantime, those basic features of due process as authorized in the prior Act (P.L. 93-380) must be maintained by the States.

It should be further noted that, when the parents or guardian of a child are not known, are unavailable, or when the child is a legal ward of the State, the State education agency, local education agency or intermediate education agency (as appropriate) must assign an individual to act as a *surrogate* for the child in all due process proceedings. Moreover, such assigned individual may not be an employee of the State educational agency, local educational agency, or intermediate educational unit *involved in* the education or care of the particular child.

Federal Sanction

If the Commissioner finds substantial noncompliance with the various provisions of this Act, with emphasis upon the guarantees for children and their parents, he shall terminate the funding to a given locality or State under this Act, as well as the funding of those programs specifically designed for handicapped children under the following titles:

- Part A of Title I of the Elementary and Secondary Education Act
- Title II of the Elementary and Secondary Education Act (innovative programs) and its successor, Part C. Educational Innovation and Support, Section 431 of P.L. 93-380
- The Vocational Education Act

SEA Authority

P.L. 94-142 requires that the State educational agency be responsible for ensuring that all requirements of the Act are carried out, and that all education programs within the State for all handicapped children, including all such programs administered by any other State or local agency, must meet State educational agency standards and be under the general supervision of persons responsible for the education of handicapped children. This provision establisheds a single line of authority within one State agency for the education of all handicapped children within each State.

This provision is included in the Act for at least the following reasons:

- to centralize accountability, both for the State itself and from the standpoint of the Federal government as a participant in the educational mission;
- to encourage the best utilization of education resources;
- to guarantee complete and thoughtful implementation of the comprehensive State plan for the education of all handicapped children within the State as already required in P.L. 93-380, the Education Amendments of 1974, as well as the implementation of the further planning provisions of this Act;
- to ensure day-by-day coordination of efforts among involved agencies;
- to terminate the all too frequent practice of the bureaucratic "bumping" of children from agency to agency with the net result of no one taking substantive charge of the child's educational wellbeing;
- to squarely direct public responsibility where the child is totally excluded from an educational opportunity;
- to guarantee that the State agency which typically houses the greatest educational expertise has the responsibility for at least supervising the educational mission of all handicapped children;
- to ensure a responsible public agency to which parents and guardians may turn when their children are not receiving the educational services to which they are entitled.

Special Evaluations

P.L. 94-142 orders a statistically valid survey of the effectiveness of individualized instruction as mandated in the legislation. P.L. 94-142 also orders the U.S. Commissioner to conduct an evaluation of the effectiveness of educating handicapped children in the least restrictive environment and orders the Commissioner to evaluate the effectiveness of procedures to prevent erroneous classification of children.

Supplanting

P.L. 94-142 carries a stipulation which permits the U.S. Commissioner to waive the provision against supplanting of State and local funds with Federal dollars when a State presents clear and convincing evidence that all handicapped children within said State do in fact have available to them a free, appropriate public education.

Employment

P.L. 94-142 stipulates that recipients of Federal assistance under this Act shall make positive efforts to employ and advance in employment qualified handicapped individuals.

Architectural Barriers

P.L. 94-142 authorizes such sums as may be necessary for the U.S. Commissioner to award grants to pay all or part of the cost of altering existing buildings and equipment to eliminate architectural barriers in educational facilities. Such provision is aimed at assuring certain handicapped children an appropriate public education in the least restrictive environment.

Preschool Incentive

P.L. 94-142 carries a special incentive grant aimed at encouraging the States to provide special education and related services to its preschool handicapped children. Each handicapped child in the State aged three to five who is counted as served will generate a special $300 entitlement. It should be noted that this incentive entitlement goes to the State education agency and must be used by the SEA to provide preschool services. Additionally, this entitlement is a separate "line item" appropriation, independent of the larger P.L. 94-142 entitlement.

Advisory

P.L. 94-142 orders that each State shall have an advisory panel to be appointed by the Governor or any other official authorized under State law to make such appointments. This panel must be composed of individuals involved in or concerned with the education of handicapped children, including handicapped individuals, teachers, parents or guardians of handicapped children, State and local education officials, and administrators of programs for handicapped children.

The panel shall have the following duties:

- advise the State education agency on unmet needs relative to the education of all handicapped children within the State;
- comment publicly on rules and regulations issued by the State and procedures proposed by the State for distribution of funds;
- assist the State in developing and reporting such data and evaluations as may assist the U.S. Commissioner.

Native Americans

Not more than one percent of the funds available under P.L. 94-142 are targeted for supporting the special education of American Indian children on the reservations serviced by elementary and secondary schools. However, the Commissioner of Education may make such a payment to the Secretary of the Interior (Bureau of Indian Affairs is within Interior) only after receiving an application from the Secretary of the Interior which meets all of those requirements contained in this summary under the heading *STATE AND LOCAL REQUIREMENTS*. Thus, for instance, the Secretary of the Interior must assure all of those educational rights for Native American children required of the States and their localities.

Private Settings

Children in private elementary and secondary schools may receive assistance for their special education under this Act if:

- such children are placed in or referred to such schools by the State or local education agency *as a means of carrying out public policy*;
- an individualized education program, as required by this Act, is maintained for such children in private facilities;
- the special education is at no cost to the parents;
- the State education agency determines that participating schools meet the standards that apply to State and local education agencies;
- the children served in such facilities are accorded all of the educational rights they would have if served directly by public agencies.

State Administration

The State education agency is permitted to reserve to itself from the total allotment to the State under this Act—in any given year—five percent or $200,000, whichever is greater, to support its administrative responsibilities.

Data

The U.S. Commissioner of Education, through the National Center for Educational Statistics, is required to provide to the Congress and the public at least annually—and is required to update annually—vital data on the educational status of the Nation's handicapped children, such as:

- children served and unserved within each disability;
- children within the regular education environment, and children who are not;
- the number of educational personnel employed, by disability category;
- number of children receiving special education instruction within residential settings, and the number of children residing in institutions having a deinstitutionalized education program.

Legislative Format

P.L. 94-142 amends the existing Education of the Handicapped Act and rewrites Part B of that Act. In that context, it is important to observe that all of the important advances made in Part B through P.L. 93-380 (Education Amendments of 1974) are retained in P.L. 94-142, and in many instances, are considerably improved upon.

Impact

P.L. 94-142 provides for an annual evaluation of the effectiveness of this legislation toward assistance in the achievement of a free, appropriate public education for all of the Nation's handicapped children.

Lifetime

P.L. 94-142 establishes a permanent authorization with no expiration date.

Prepared by The Council for Exceptional Children, Reston, Virginia

APPENDIX B

METHODS OF STATE FISCAL SUPPORT

Several methods of funding have been used by states to assist local educational agencies in financing programs and services for exceptional children: (a) unit basis, (b) weighted formula, (c) percentage reimbursement, (d) reimbursement for personnel, (e) straight sum reimbursement, and (f) excess cost formula (Thomas1973a).

Unit basis. Some states reimburse a fixed sum on a unit basis whereby the unit is defined as a set number of children assigned to a special class. Districts will certify the number of students enrolled in special classes. A unit of funds may also be allocated for administration on the basis of one unit for a set number of

classroom units. Units may also be apportioned for ancillary services. . .

The growth of units for particular special programs have been limited in the past to a certain percentage annually, which inhibits the development of new exceptional child programs. This has promoted the development of special classes and has made resource room programs or special assistance in the regular classroom extremely difficult to reimburse. Other problems have been encountered in using the unit system (Thomas, 1973a):

1. Maximization of class size to decrease per pupil cost.
2. Inability of small school districts to generate enough special education classroom units to qualify for units for classroom ancillary services and administration.
3. Nonreimbursement of higher costs during the first year of a program.
4. Lack of funding in most states for costs incurred in mainstreaming.
5. Inappropriate placement of children in a program with a lower per pupil expenditure when units are allocated for differing class size on the basis of a child's disability.
6. Same reimbursement for all programs regardless of cost and/or quality.

Some of these problems may be overcome by the establishment of statutory limits on class size or by a gurantee to each district of at least one classroom unit for each category of exceptionality or of a unit to be shared with another district. Districts may also share ancillary service, administrative, and supervisory units. The dollar amount allocated with new units could be greater for the first year only.

Weighted formula. A state may elect to fund special education programs by using a system of weights, with the per pupil expenditure of the least expensive school program (regular elementary programs) serving as a base of 1. The regular per pupil expenditure multiplied by the weight for each category of program . . . equals the amounts of funds received per child. This method conceptually allows for the full cost of special programs in the general state aid formula.

A problem arises with the use of a weighted system when average state costs serve as the basis for the development of cost indices, rather than an individual cost index for each district. In some districts the allocation will be too large and in others it will not offset expenditures. There is also great variability in each child's need within each category of exceptionality, generally associated with the severity of condition . . .

Percentage reimbursement. A state may elect to allocate funds to districts using the percentage reimbursement pattern. If it does, it will reimburse a set percentage of all costs incurred in providing special education programs. Assuming that all costs may be accounted for, it overcomes some of the programing problems encountered in the previous methods. However, several drawbacks have been noted.

Since per pupil program costs vary, it will be less expensive to educate a child in one categorical program by using one delivery system than it will be using another. Thus, if the percentage that is reimbursed is low, a school district may still find its outlay in certain programs excessive. This will lead to inappropriate placements. From a state level viewpoint, without a per pupil expenditure cap, it would appear that the total allocated state dollars could be unlimited, However, the level of state appropriations necessarily sets a limit, and those funds are prorated on the basis of the percentage reimbursement formula.

Reimbursement for personnel. In this procedure, a set amount of money may be allocated to offset the costs of special education teachers, administrators and supervisors, pupil personnel workers, and other professional and noncertified support staff. A reimbursement program for personnel alone does not recognize all direct and indirect costs in special education, although it is conceded that personnel costs represent the single most critical factor in financing. The outlook for mainstreaming using this method of financing [is not] optimistic, since mainstreaming requires the presence of the exceptional child in the regular education program to the extent appropriate and those costs are not paid by the state when a child is counted either as an exceptional or normal child. Without class size limitations, local educational agencies may be encouraged to maximize class size to decrease per pupil expenditures.

Straight sum reimbursement. This form of reimbursement is simply a set amount of money, which may vary according to the exceptional condition, allocated per exceptional child served in each district. It has an advantage for local

education agencies over the unit pattern since no set minimum number of served children is required before state monies are distributed. Straight sum reimbursements often have little relationship to realistic program costs. As with other patterns, there is a tendency to label children for fiscal advantage and maximize the size of classes.

Excess cost pattern. The excess cost pattern of funding special education exists in several states and is being considered by a number of others. Excess cost may be defined as the amount by which the per pupil expenditure for exceptional children exceeds the per pupil expenditure for all other children.

The total amount to be reimbursed would be that difference multiplied by the number of exceptional children. Depending on the level of funding, excess cost may be completely reimbursed, reimbursed up to a dollar amount ceiling, or reimbursed on a percentage or prorated basis. When the state is willing to appropriate sufficient funds to cover all excess costs, theoretically the district is encouraged to make the best placement for the child because doing so causes no extra financial burden. Prohibitive costs do not becomes a major factor in deterring a child from receiving the full range of services. When the payment, however, is a percentage of excess costs, the school districts encounter the same problem as that discussed under the percentage approach. (Thomas, 1973a, p.477)

Difficulty is encountered in determining just what is excess cost and ensuring comparability between districts. Standardization between districts requires a common program cost and element format and accounting procedures necessary to calculate excess cost. Of special concern must be the problem of separating out the cost of educating exceptional children provided in mainstreamed settings, where exceptional children spend part or full time in regular classes with supplementary services provided in those settings. Also of concern is the allocation or proration of indirect costs.

If state regulations contain imprecise definitions of exceptional conditions, there will be great variability between districts in the manner of determining a child's eligibility for special education services. This will lead to the improper labeling of children and a financial advantage or disadvantage for some districts.

The reimbursement of excess cost has been viewed as a method whereby the state fully funds extra instructional costs of special education programs where the pupil, teacher, or size of the instructional group are units for determining excess cost. Excess cost could be funded by basing it on (a) state guidelines to determine actual allowances, (b) average excess costs of the preceding year in a sample of exemplary districts, or (c) state guaranteed (foundation) level of support for the current year.

Note: From "Financing the education of exceptional children" by J. J. Marinelli in *Public policy and the education of exceptional children* edited by F. J. Weintraub, A. Abeson, J. Ballard, and M. L. LaVor. Copyright 1976 by The Council for Exceptional Children.

PROBLEMS OF THE SEVERELY AND MULTIPLY HANDICAPPED

Awareness Paper Based on a Paper By

Frederick Fay, Ph.D.
Research Rehabilitation Institute
Boston, Massachusetts

TABLE OF CONTENTS

	Page
Introduction	289
Service Delivery Systems	291
Barriers to Community Life	302
Transportation Barriers	303
Architectural Barriers	305
Geographic Mobility	306
Rehabilitation: Self-Care and Vocational Objectives	307
Appendices	310

ACKNOWLEDGMENT

The White House Conference on Handicapped Individuals wishes to thank the following council members for their extensive assistance: Dr. Paul Hoffman; Jesse Brown; Albert Pimentel; Burt Risley; and Ms. Jayne Shover. Special thanks also go to members of the Technical Review Team: Ms. Marcia Burgdorf, Director, Developmental Disabilities Law Project; Ms. Eunice Fiorito, Mayor's Office for the Handicapped, (New York); Dr. James Folsom, Director, Rehabilitation Medicine and Surgery, Veterans Administration; Lex Frieden, University of Texas; and Ms. Essie Morgan, Chiet, Socio-Economic Rehabilitation and Staff Development, Spinal Cord Injury, Veterans Administration.

INTRODUCTION

Over 10,000,000 of our citizens are confronted daily by problems of the greatest magnitude seldom faced by the rest of our society. They are our people who have severe or multiple handicaps. In many instances, they are confined to their apartments, homes or other residences because physical barriers and the lack of adequate services enforce their isolation. If they can leave their homes, more often than not, they are prisoners of their neighborhoods, because the public transportation system, accessible to all others, is either too complex for them to negotiate or it is physically inaccessible to them. They are discriminated against by employers, so they seldom earn wages with which to maintain themselves and/or their families in dignity and in decency. Public health, welfare and social service programs lack the elements and/or funding that would enable these 10,000,000 people with severe handicaps to achieve maximum functional capacity leading to independence of others in self care, in mobility and in coping with the other aspects of normal living. And, finally, social attitudes directed at disability and "the handicapped" result in the exclusion of the disabled from participation in community, cultural and recreational activities essential to a full and complete life.

How to overcome and how to change these conditions are the concerns of our citizens with severe or multiple handicaps, and should be the concerns of our entire society.

The Severely and Multiply Disabled

There is no one universally accepted definition of "severe disability," nor is there consensus as to the bases upon which to develop such a definition. Some people equate "severe disability" with certain mental and physical impairments, others with inability to perform various tasks or engage in specific activities. A commonly agreed upon definition of "multiply disabled" is even more elusive. A simplistic definition of "multiply disabled" is having more than one physical or mental disability. Thus someone who is both deaf and blind, or someone who is both cerebral palsied and mentally retarded is frequently labeled "multiply disabled." To compound matters, each of our public and voluntary health, education, rehabilitation and social programs has its own definition related to its objectives and best suited to its operations. For example, for one of its programs, the Office of Education defines a person who is severely or multiply disabled as:

> "One who because of the intensity of his physical, mental, or emotional problems, or combination of such problems, needs education, social, psychological, and medical services beyond those offered by traditional regular and special educational programs in order to maximize his full potential for useful and meaningful participation in society and for self-fulfillment."

The Rehabilitation Act defines "severe handicaps" for vocational rehabilitation purposes as a

> "disability which requires multiple services over an extended period of time and results from amputation, blindness, cancer, cerebral palsy, cystic fibrosis, deafness, heart disease, hemiplegia, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia and other spinal cord conditions, renal failure, respiratory or pulmonary dysfunction, and any other disability specified by the Secretary in regulations he shall prescribe."

The Social Security Act (Title II, Disability Insurance and Title XVI, Supplementary Security Income) defines a disabled person as one who is

> "unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months."

or if blind, who has

> "central visual acuity of 20/200 or less in the better eye with use of correcting lens."

To qualify for services under The Developmental Disabilities program an individual must have a disability

> "(A) attributable to (i) mental retardation, cerebral palsy, or epilepsy, or (ii) attributable to other neurological conditions found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals; (B) originated before the individual attained age 18 and has continued or can be expected to continue indefinitely; and (C) constitutes substantial handicap to the individual."

To qualify under the Direct Loan Program for the Elderly and Handicapped of the Department of Housing and Urban Development an individual must have

> "An impairment which (A) is expected to be of long duration, (B) substantially impedes his ability to live independently, and (C) is of such a nature that such ability could be improved by more suitable housing conditions." (Also included are developmentally disabled individuals.)

For the programs under Titles IV and V of the Rehabilitation Act of 1973, as amended, a handicapped individual is defined as

> "Any person who (A) has a physical or mental impairment which substantially limits such person's functioning in one or more of such person's major life activities, (B) has a record of such an impairment, (C) is regarded as having such an impairment."

The programs under Title V of the Rehabilitation Act to which this definition applies are designed to (a) expand employment opportunities for handicapped individuals in government and in industry and (b) eliminate barriers in the environment which impede handicapped people in employment, housing and transportation and (c) prohibit discrimination against handicapped people in any program or activity receiving Federal assistance.

The Office of Handicapped Individuals (of the Department of Health, Education and Welfare) established by Title IV of the Rehabilitation Act with responsibility for examining what is currently being done and planned for handicapped individuals throughout the Federal government developed and applies the following definition:

> "A handicapped individual is one who has a physical or mental impairment or condition which places him at a disadvantage in a major life activity such as ambulation, communication, self-care, socialization, vocational training, employment, transportation, adapting to housing, etc. The physical or mental impairment or condition must be static, of long duration, or slowly progressive."

This definition excludes conditions of the get-sick-get-well variety. It also excludes conditions which have little or no impact on the individual. It is felt that the very broad definition is necessary for planning purposes. It is intended to provide an umbrella under which all programs with more narrow focus and very particular definitions can be accomodated.

Thus it can be seen that many factors enter into the identification of people as "disabled," "severely disabled," and "multiply disabled." Among these factors are body impairments, the functional limitations resulting from the impairments, the environment, education, age, community and employer attitudes and, equally if not of greater importance, the self image of the person with the impairment. People differ in their capacities to cope with impairments, and therefore, even between people with identical conditions, the severity of the disability may vary. Moreover, many persons who are blind, deaf, retarded and using wheelchairs object to the stereotyping of all such persons as "severely disabled."

The problems of persons with multiple disabilities are included among the problems of persons with severe disabilities. Therefore, for this paper the term "severely disabled" will be used to cover both.

Estimates of Severely Disabled Population

In authorizing the President to call a White House Conference on Handicapped Individuals, the Congress found, among other things, that "there are seven million children and at least twenty-eight million adults with mental or physical handicaps."

Estimates of the number of disabled individuals in the United States vary, as the surveys from which the estimates are derived use differing definitions of disability and survey methods. As a consequence, there are no exact, hard data concerning the number of people who might make up the "disabled," the "severely disabled" and the "multiply disabled" population. There is great need for the development of a system that will identify the incidence and prevalence of severely handicapped individuals in the United States, as well as other information essential for planning programs to meet their needs.

The Urban Institute, in a recent study of individuals with the most severe handicaps asked various voluntary agencies to report the "most severely disabled" incidence and prevalence data for the population of concern to them. Some of their responses are set forth in Appendix A. Using these and data from other studies, The Urban Institute estimated the number of individuals with the most severe handicaps in the United States in 1975 to be over 10,000,000 as follows:

Noninstitutional population ..	8,280,000
Under age 18	180,000
18-64	4,200,000
65 and over	3,900,000
Institutional Population	1,787,000
Total U.S. population with most severe handicaps	10,067,000*

The conditions that account for the greatest amount of activity limitation for the severely disabled group aged 18-64 are: (1) heart conditions, (2) arthritis and rheumatism, (3) impairment of back and spine (except paralysis), and (4) mental and nervous conditions. The causes of mobility limitation are disaggregated by smaller age groups. Causes of mobility limitation in the 18-44 age group are: (1) paralysis, (2) impairment of lower extremities and hips, (3) impairment of back and spine, and (4) arthritis. For the 45-64 age group, arthritis and rheumatism are the leading causes, followed by heart conditions, paralysis and impairments of lower back and spine.†

The Urban Institute estimates that by 1984, the total number of severely disabled and moderately disabled individuals will increase to 38,648,000, of which almost 13,000,000 will be severely disabled.*

SERVICE DELIVERY SYSTEMS

Public Service Agencies

The government programs serving people who are handicapped are extensive and varied, designed to serve different purposes and relying on different definitions of the concept of disability. Some programs are dedicated exclusively to disabled people; others utilize program earmarks or components for the disabled. Some are limited to specific disability groups, while others are unrestricted in the disabled people they serve. Some focus on severely disabled people alone; others focus on all disabled people. They use varying methods in providing their services and the extent to which services are provided varies considerably among the programs.

Prior to 1973, there was no single Federal agency responsible for an overall review and comprehensive look at the Federal programs and policies affecting disabled people. The Rehabilitation Act of 1973, in recognition of this deficiency, created The Office for Handicapped Individuals within the Department of Health, Education and Welfare, responsible, among other things for review, coordination, information and planning pertaining to the policies, programs, procedures and actities of the various programs for the physically and the mentally handicapped.

The Office for Handicapped Individuals surveyed all Federal programs which serve the handicapped. This study concluded in March, 1975, identified 75 programs whose primary misssion is to serve the handicapped; 6 programs not exclusvely for the handicapped, but which emphasize service to handicapped individuals; and 45 programs which serve handicapped people on the same bases as others. A tabulation of these programs will be found in Appendix A.

Nearly all of the programs identified in Appendix B as benefitting disabled people also

*Report of the *Comprehensive Service Needs Study*—The Urban Institute, Washington, D.C.

†Charles S. Wilder, *Chronic Conditions and Limitations of Activity and Mobility 1965-1967*, NCHS Series 10, No. 1, January 1971.

*Working Paper 0981-02 *Modeling and Forecasting Disability Information*, submitted to the Department of Health, Education and Welfare, June 9, 1975. The Urban Institute.

benefit those people who are severely handicapped. Most of the services for the severely handicapped people are in the form of basic support (income maintenance), health and medical care, social services, educational services and vocational rehabilitation. By far the greatest expenditures are for income maintenance and health and medical care. Payments for educational services, vocational rehabilitation and other related and direct services are minimal in comparison.

The Disability Insurance, the Supplemental Security Income and the Aid to Families with Dependent Children programs under the Social Security Act are the major income maintenance programs for individuals who are severely disabled. The first provides monthly cash payments to eligible persons and their dependents, when the covered person suffers a physical or mental impairment that has lasted, or is expected to last, 12 months or more, and the impairment prevents any substantial employment. Supplemental Security Income is a program of direct payments to persons over the age of 65, or blind, or totally disabled who, on the basis of their monthly income and some resources, are below a certain level of support. The Aid to Families with Dependent Children program provides financial assistance to families with needy children where that need is based upon incapacity, death, continued absence or chronic unemployment of a parent. Other Federal programs providing income maintenance payments, compensation and pension payments which benefit severely disabled people are the Veterans Administration programs, the Black Lung Program, the Federal Workers' Compensation Programs, Food Stamps and various Federal retirement programs.

With prolonged and severe disability, the financial resources of the individual so affected and his family are soon exhausted. Thus, people with severe handicaps have fewer resources than persons without such handicaps and generally are completely dependent upon the resources of an institution or upon payments from income maintenance systems for their survival. Often these payments are insufficient to meet basic needs. Moreover, the income maintenance programs contain provisions that serve as disincentives to employment. For example, the value of certain benefits such as attendant care, Medicare or Medicaid, can amount to more than the recipient is able to purchase through his earnings, after meeting basic food, clothing and shelter needs. It is essential, therefore, that incentives for vocational rehabilitation be built into the income maintenance programs to provide employment opportunities for all severely disabled people who are or who can become capable of working full or part time. It is also essential that the level of the income maintenance payments be such as to maintain in decency and health those persons who are dependent upon such help.

Maintenance of health in general for those who are severely disabled involves attention to both conditions which require hospitalization as well as minor medical problems. These ongoing health problems may be related to the person's disability or the problems may be common to all individuals, such as infections, malfunction of certain internal processes, dental problems, etc. The high cost of medical care is felt by most Americans, but to a person severely disabled, it can especially limit access to such care, particularly if the high cost of medical care is compounded by the cost of special transportation.

Many persons who are severely disabled will qualify for either Medicare or Medicaid coverage. Medicare is a Federal program of uniform benefits to cover the reasonable cost of hospitalization and medical care for the aged and disabled. The program is authorized by Title XVIII of the Social Security Act. Persons eligible include all those over age 65. Beginning in 1974, eligibility was extended to include all Social Security Disability Insurance beneficiaries who have been disabled for two years or more and persons with permanent kidney failure when they need maintenance dialysis treatments or a kidney transplant. People with permanent kidney failure are among those persons considered "severely disabled." Moreover, most are unable to pay for their life-sustaining dialysis which if done at home will cost over $5,000 per year and $30,000. per year if done in the hospital. Medicare under Part B Supplementary Medical Insurance (SMI) requires an annual $60 deductible, after which the beneficiary is covered for 80% of the allowed charges. Certain prosthetic devices are also covered under this section. Those enrolled in SMI must also agree to pay the monthly premium of $6.30, or have this paid by a state welfare agency.* These charges often

*Ralph Treitel, "Rehabilitation of the Disabled", *Social Security Bulletin*, Vol. 34, No. 3, March 1971.

represent financial barriers to care, particularly in those states that do not pay the monthly premium.

For those who qualify by reason of their yearly income, Medicaid pays many medical expenses, but states' restrictions vary as to who is covered and what kinds of services are paid. An additional problem in Medicaid coverage is the disincentive it represents to seeking and holding a job. Because the costs of health care for severely disabled persons are so much greater than the averge, many find that only the most highly paying jobs can provide enough income to allow them to cover their own medical costs.

Workmen's Compensation, another source of financing medical care, covers a wide range of medical and rehabilitation services to the injured worker. However, some states place statutory and administrative limits on medical benefits. Other programs providing medical payments and services to the disabled include: the veterans Administration programs, Maternal and Child Health Services, Community Mental Health Centers Champus, Crippled Children Services and the medical component of the Vocational Rehabilitation program.

A basic need of many disabled people is to remove economic dependency upon others or upon income maintenace programs through services which help the disabled person achieve gainful employment or at least partial self-support. The primary program which delivers these services is the Vocational Rehabilitation Program. This program operates in all fifty states and in the District of Columbia, Puerto Rico, Guam, The Virgin Islands and The Trust Territory of the Pacific Islands. Thirty-one of the state agencies administer both the general and blind programs, while in twenty-four jurisdictions, the general and blind programs are administered separately. Over 11,000 counselors provide services through a network exceeding 1,000 district and local offices.

Eligibility for services is based on a study of pertinent data sufficient to determine an individual's rehabilitation potential and the existence of a disability constituting a substantial handicap to employment. Further studies, as necessary, assist counselors and clients in jointly developing the individualized written rehabilitation programs, which, in part, specify services to be provided, and objectives and employment goals to be achieved. The rehabilitation counselor is responsible for the eligibility determination, developing with the handicapped person an individualized rehabilitation plan, managing the arrangements for services, counseling and guiding the individual, staying with that person through successful placement on the job, and providing any necessary post-employment services to assist in maintaining employment.

In addition to counseling and guidance, the range of services includes: physical and mental restorative services, such as medical and corrective surgical treatment, hospitalization, prosthetic, orthotic, and other assistive devices, and physical and occupational therapy; psychological services; training, including personal and work adjustment; maintenance; transportation; reader services and orientation and mobility services for the blind; interpreter services for the deaf; and post-employment services.

The provision of services involves virtually the full span of community resources. Private physicians, public and private hospitals, specialized clinics, rehabilitation centers, sheltered workshops, public and private educational institutions, and employers, are but some of the resources which are regularly drawn into effective rehabilitation. Handicapped individuals are supposed to be placed in employment consistent with their capacities and abilities in the competitive labor market, the practice of a profession, self-employment, homemaking, farm or family work, sheltered employment, homebound employment or other gainful work. The essence of the vocational rehabilitation program is to arrange and direct all appropriate resources in a coordinated and meaningful way to bring the handicapped person to the highest functioning level.

Vocational Rehabilitation agencies rely on rehabilitation facilities for a great proportion of services. Consequently, the success of the VR program is dependent on the growth and effectiveness of rehabilitation facilities which provide evaluation, treatment, and training particularly to the severely disabled who could not be effectively rehabilitated without the assistance of these operations. Facilities include sheltered workshops, comprehensive rehabilitation centers and a variety of centers for the treatment of specific disabilities such as disabilities in speech, hearing, sight and mental retardation.

The legislative base for the Vocational Rehabilitation Program is The Rehabilitation Act of 1973, as amended by The Rehabilitation Act Amendments of 1974.

The major program established by the Rehabilitation Act of 1973 is the grant-in-aid program (Title I) which provides 80% Federal matching to State Vocational Rehabilitation agencies for expenditures made by those agencies under the State Plan for the provision and administration of vocational rehabilitation services. The Federal appropriation in fiscal year 1975 for the State-Federal program was $680 million, plus $23 million in formula grant funds for innovation and expansion grants. An additional $132,226,000 was provided to RSA through authorizations in the Social Security Act for the rehabilitation of Social Security Disability Insurance and Supplemental Security Income beneficiaries. Appropriations for discretionary grant authorities—research, evaluation, training, facilities improvement, and special projects and demonstrations—amounted to $58,145,000 in fiscal year 1975. Thus in FY 1975, the total obligation of Federal funds for support of vocational rehabilitation programs was $893,371,000.

Program emphasis in 1975 in the basic State grant program was on provision of services to the severely disabled. The allocation of financial resources in 1975 reflects the importance of services for the severely handicapped. Of the basic support expenditures approximately $160 million (34%) went for rehabilitation of the severely disabled. Other expenditures for the severely disabled include: Innovation and Expension grants ($23 million); service projects, approximately 50% ($6.9 million) of funds available; research and development, approximately 75% ($15 million), and training, approximately 75% ($8.625 million).*

During FY 1975, State vocational rehabilitation agencies rehabilitated 324,039 persons, a decline of 37,099 and 10.3% below the number of rehabilitations registered in FY 1974 (361,138). The economic recession, inflation and greater costs in serving the severely disabled were, undoubtedly, major factors in this decline, the first year in the past twenty-one years.

Included in the total of 324,039 rehabilitations were 115,746 persons (35.7%) who were deemed severely disabled. This represents an increase of 1.5 percent over FY 1974, when 113,997 severely disabled persons were rehabilitated.†

Until more precise statistical data are available, it is not possible to state with any degree of accuracy how many of the 10,000,000 people with severe disabilities could benefit from and need vocational rehabilitation services in order to return to work or to engage in work for the first time. However, it is reasonable to assume that the number of such people far exceeded the approximately 116,000 rehabilitated into employment by the Vocational Rehabilitation agencies in 1975. But the state vocational rehabilitation agencies and the facilities which they utilize for services will not be able to reach and serve increased numbers of severely disabled people unless the funds for rehabilitation purposes are vastly increased. In addition, funding for research, demonstration and training must also increase if the national rehabilitation effort is to be responsive to the needs of the people who are severely disabled. In a recent study, the Urban Institute estimated that of the $21.5 billion that was spent to assist the 10-11 million severely disabled people in 1973, less than $.4 billion or about 2% of the total budget was spent for vocational rehabilitation services to this group.*

A major concern of consumers and providers with respect to the vocational rehabilitation system is what is commonly called the "numbers game." Potential consumers of VR services who have severe disabilities, and who are frequently ignored because the VR counselor is busy with "easy rehabs," have been quite critical of the "creaming" that takes place. Even with the Rehabilitation Act of 1973's priority on the severely handicapped, many VR counselors in the field still feel pressure for quantity rather than quality.

In the Comprehensive Needs Study's survey of rehabilitation providers the problem of rehabilitation closures was seen as a major impediment to serving individuals with severe handicaps. The fact that the VR agency is "required to rehabilitate the maximum number of disabled to retain its appropriation and support" is, in great part, what leads to the "inappropriateness of rehabilitation quotas (stated and implied) imposed upon VR counselors." To correct these major impediments, a policy option is the implementation of a weighted case closure system in VR to provide greater incentive for working with the severely handicapped.

*Annual Report for FY 1975. Rehabilitation Services Administration, Department of Health, Education and Welfare.
†*Ibid.*

*Report of the *Comprehensive Service Needs Study*, The Urban Institute.

Whether it makes more sense to "weigh" the difficulty of the case at the end of the rehabilitation program, upon closure, or at the start of the program, upon acceptance and evaluation, is an open question. But the introduction of an objective measurement system that takes into account such factors as the client's employment history, economic status, physical functioning, psychological adjustment, and social competency, could properly weigh the counselor's efforts.

The Veterans Administration and other Federal and State agencies conduct many programs that provide substantial benefits and services to disabled veterans, especially to those veterans who are severely disabled. Among these benefits and services are:

- Comprehensive health and medical care, including hospitalization, outpatient medical treatment, outpatient dental treatment, and the provision of prosthetic appliances.
- Disability compensation and disability pensions.
- Nursing home care and domiciliary care.
- Electronic and mechanical aids and guide dogs to blinded veterans, including payment of the cost of training the veteran in using the dog.
- Vocational rehabilitation and educational training.
- Specially adapted housing assistance for the severely disabled veteran having distinctive housing needs, such as wide doors to accommodate a wheelchair, ramps instead of steps, oversized and especially equipped bathroooms, etc.
- Funds for the purchase of an automobile and necessary adaptive equipment.
- Mortgage insurance, property tax abatement, and commissary and exchange privileges.
- Special allowances for aid and attendance if the veteran is so disabled as to require aid and attendance of another person.
- Special consideration and services in job placement.

Certain conditions need to be met by the veteran to qualify for the services and benefits described above. For some programs, a qualifying requirement is that the disabling condition be service connected or be of certain severity. For example, hospitalization is available to all veterans, but veterans needing hospitalization because of injuries or disease incurred or aggravated in line of duty in active service have top priority for admission for treatment of the service-incurred or service-aggravated disability.*

The services and benefits provided by the Veterans Administration reach millions of disabled veterans. For example, in 1975, 2,220,169 disabled veterans received disability compensation for disability incurred or aggravated while on active duty, and an additional 1,006,127 disabled veterans received disability pensions for non-service connected disabilities. In that same year, the Veterans Administration received 2,069,000 applications for hospital care. About 73% of the applicants were accepted for hospital care, and many others received ambulatory care. The Veterans Administration health care system in 1975 provided care in 171 hospitals, 213 outpatient clinics, 85 nursing homes, and 18 domiciliaries. Veterans were also given care under VA auspices in non-VA hospitals and in community nursing homes. In addition, the VA authorized, on a free-for-service basis, visits to non-VA physicians and dentists for outpatient treatment, and supported veterans under care in 8 hospitals, 31 nursing homes, and 38 domiciliaries operated by 31 States.†

The veteran with a spinal cord injury receives early and special comprehensive care through the network of Spinal Cord Injury Centers operated by the Veterans Administration, in selected Veterans Administration Hospitals throughout the country. The Veterans Administration makes great effort to facilitate expeditious transfer of veterans with spinal cord injuries from military and VA hospitals to VA hospitals with the specialized Centers. In 1975, 1,007 veterans with spinal cord injuries were admitted to VA hospitals for the first time, 449 of whom were admitted within six months of injury. In 1975 the VA hospital, Brockton, MA., activated a 60 bed Spinal Cord Iniury Center, emphasizing comprehensive physical, vocational and community oriented rehabilitation. This activation brought the number of spinal cord injury beds to 1,390. Since World War 11 the Veterans Administration has had a network of spinal cord injury centers, while only in the past three years

*_Federal Benefits for Veterans and Dependents_ Veterans Administration, Washington, D.C. This publication describes the various programs for veterans and the qualifying conditions.

†_Annual Report_ Administrator of Veterans Affairs, Washington, D.C. Report on the activities of the Veterans Administration for the fiscal year ending June 30, 1975.

has such an approach been federally funded for civilians. While the population of spinal cord injured veterans is one-ninth that of the civilians in size, there are currently 14 VA spinal cord injury centers and 10 civilian centers.

Vocational Rehabilitation is another service of the Veterans Administration which is of particular importance for the veteran who is severely disabled. This service is designed to assist service disabled veterans in need of rehabilitation to overcome the handicapping effects of their disabilities and to prepare for, obtain and held productive employment. Through individualized counselling, each veteran is helped to select a suitable vocational objective and to plan a program of rehabilitation training to achieve the goal selected. The VA provides all necessary medical, prosthetic and other services and special supplies and equipment for successful rehabilitation. VA rehabilitation staff maintain continuing close contact with the veteran throughout the training to assist as needed. While in training, the veteran receives a monthly subsistence allowance in addition to disability compensation. The VA also pays the cost of tuition, books and supplies to the training facility. On completing training, the veteran is helped to secure and maintain employment in the field for which he or she is trained.

During 1975 the eligibility requirements for vocational rehabilitation applicable to certain service-disabled veterans were liberalized, making benefits potentially available to many more veterans. Prior to the enactment of Public Law 93-508 veterans having a compensable disability rated less than 30 percent which resulted from service after the Korean conflict, or during the period between World War II and the Korean conflict, could be provided training under the vocational rehabilitation program only if the service connected disability were found to constitute a pronounced employment handicap. Public Law 93-508 eliminated this requirement so that the determination as to need for vocational rehabilitation is now made on the basis of the same criteria for all veterans otherwise eligible.

Public Law 93-508, as subsequently amended by Public Law 93-602, also increased the subsistence allowance for vocational rehabilitation trainees approximately 22.7 percent over the rate in effect prior to September 1, 1974. The impact of these liberalizations on the use of vocational rehabilitation program showed an increase over the numbers so served during January through June 1974. For the year as a whole, however, the rehabilitation training program decreased in size, with a total of 24,840 veterans in training, 7.9 percent fewer than the 26,974 enrolled in FY 1974. This represents a continuation of the decline that has occurred each year since FY 1972, when the number of veterans in rehabilitation training totaled 31,635, the peak for the Vietnam era. Of those in training, 18,487 were attending colleges and universities, 4,855 were in trade or technical schools or in special training situations, such as rehabilitation centers and 1,498 were in on-the-job and on-the-farm training.

As mandated by law, the extended period of eligibility during which seriously disabled veterans can be provided vocational rehabilitation terminated June 30, 1975 for most World War II and Korean conflict veterans. Special efforts were made in cooperation with the Rehabilitation Services Administration, Department of Health, Education and Welfare to ensure that those seriously disabled veterans who were enrolled in training under the VA program on the termination date would be continued in training under the State-Federal program, and that veterans applying subsequently to initiate training would receive sympathetic consideration.

In 1975, as in the previous year, intensive outreach and follow-up efforts were directed toward encouraging veterans in need of vocational rehabilitation services to participate in the program and toward ensuring that such participation culminates in rehabilitation, as evidence by successful employment. As part of this effort, VA continued its collaboration with National Alliance of Businessmen and the Department of Labor in a joint project to identify and assist service disabled veterans in need of training or employment assistance.

State programs under Title XX of the Social Security Act provide a broad range of social services for people who are blind, disabled, and aged. The stated goals of the program are (a) to help people become or remain economically self-supporting; (b) to help people become or remain self-sufficient; (c) to remedy neglect, abuse, or exploitation of children and adults unable to protect their own interests; (d) to prevent or reduce inappropriate institutionalization by providing community based, home based, or other form of less intensive care; and (e) to

secure institutional care when necessary. Eligibility guidelines are established by the federal government. States may include anyone who receives cash payments under Aid to Families with Dependent Children (AFDC) or SSI, or anyone who has an annual income that does not exceed 115% of their State's median income as adjusted for family size. Variance in eligibility requirements by State is not simply the result of different median incomes, however. States may choose not to offer services to any individuals who do not qualify for income maintenance programs, or they may vary their eligibility requirements by setting different income limits for different services or different categories of beneficiaries or by limiting eligibility for a specific service to a specific category of eligible persons.

States are free to provide a wide range of services designed to meet the five program goals. Examples of the social services that may be provided under Title XX include homemaker services, foster home services, after-school care for children, family planning services, chore services for the elderly, emergency shelter service for runaways, family counseling, transportation services, halfway houses, part-time care for the elderly and handicapped children, and information and referral services. Benefits vary considerably among the states, and gaps in services may appeear, since each state is required to provide a minimum of only one service directed at each of the stated Title XX goals, and three services for SSI recipients. Types of care settings are left to the discretion of states as long as they are appropriate to the stated goal in question.

Private Service Agencies

In the United States, there are hundreds of private agencies, associations, fraternal and religious societies, veterans' groups and self-help and consumer organizations, all having a full or partial purpose of serving the needs of people who are handicapped. Membership in these organizations total in the hundreds of thousands. Most are national organizations with state or local affiliates; some are purely community organizations; and a few are international in scope.*

Many of these private associations initiated the earliest programs in the United States for handicapped people, and have had long years of continuous service. Among those established in the nineteenth century which are still in operation are: The Perkins School for the Blind (1829), The American Association of Instructors of the Blind (1853), The American Printing House for the Blind (1858), Gallaudet College—the world's only liberal arts college for the deaf (1864), The American Association for Mental Deficiency (1876), The National Association of the Deaf (1880), The Alexander Graham Bell Association for the Deaf (1890), The Industrial Home for the Blind (1893), and The American Association of Workers for the Blind (1895).

The first three decades of the twentieth century witnessed the establishment of a large numer of voluntary agencies, including The Goodwill Industries of America (1902); The American Lung Association (1904); The American Leprosy Mission (1906); The National Society for the Prevention of Blindness (1908); The National Association for Mental Health (1909); American Cancer Society (1913); The International Association of Industrial Accidents Board and Commissions (1914); The American Occupational Therapy Association, The American Orthotic and Prosthetic Association and the I.C.D. Rehabilitation and Research Center in 1971; The Menninger Foundation, The National Association of Speech and Hearing Agencies and The American Legion in 1919; Disabled American Veterans (1920); The American Physical Therapy Association, The American Foundation for the Blind, and The National Easter Seal Society for Crippled Children and Adults in 1921; The National Rehabilitation Association (1925); and Seeing Eye, Inc., in 1929.

From World War II to the present, a still larger number of private agencies concerned with the problems of disability were established. Among these are hundreds of rehabilitation

*(a) *Directory of Organizations Interested in the Handicapped*—Committee for the Handicapped—People to People Program, Suite 610 LaSalle Bldg., Connecticut and L Streets, N.W., Washington, D.C. 20036

(b) *Directory of Organizations of the Handicapped*—Massachusetts Council of Organizations of the Handicapped, Tufts-New England Medical Center, Box 337, 171 Harrison Avenue, Boston, Massachusetts 02111

(c) *Directory of Agencies Serving the Visually Handicapped in the United States*, American Foundation for the Blind, 15 West 16th Street, New York, New York 10011

(d) *American Annals of the Deaf*, 5034 Wisconsin Avenue, N.W., Washington, D.C. 20016

(e) *Encyclopedia of Associations*, Gale Research Tower, Detroit, Michigan 48226

centers and rehabilitation workshops; The Association of Rehabilitation Facilities; The United Mine Workers of America Welfare and Retirement Fund which includes an extensive rehabilitation service as does The Department of Community Services of the AFL-CIO; The International Committee Against Mental Illness, The Epilepsy Fouccation of America, United Cerebral Palsy Associations, Inc. and other national organizations with state and local affiliates and concerned with a specific disability.

The chronology of the establishment of these agencies parallels the historical development of the country as a whole—a concern in the nineteenth century for the individual who physically was not so rugged a frontiersman as others; a concern in the early part of the twentieth century, as the nation become more industrialized, with the disabled worker; a concern in 1918 with the rehabilitation of the soldier and sailor disabled in World War I resulting in passage of The Soldiers Rehabilitation Act which is the basis for the rehabilitation programs for members of the armed forces disabled in World War II, Korea and Vietnam; and in the second and third quarters of this century, a concern with all people who are disabled—the young and old—with all aspects of disability and with service delivery systems including expansion of the role of persons with disabilities themselves, the "consumers" of service, in the planning, delivery and evaluation of the system.

In recent years persons with disabilities have begun to organize themselves as an effective minority seeking their full civil and human rights. National organizations of the blind and of the deaf have been strong advocates for years. In the past two decades, the Paralyzed Veterans of America, The National Paraplegia Foundation, Disabled in Action and others have emerged as organizations of, by and for the physically handicapped. State coalitions have developed that cut across as many as 40 disability groups. Within the past two years, many of the national consumer organizations and state coalitions have joined together to cooperatively solve problems common to all citizens with disabilities. Under the umbrella of the American Coalition of Citizens with Disabilities their stated purpose is "to promote social and economic well-being and to assure the full exercise of human and constitutional rights of citizens with disabilities."

The thousands of private organizations and facilities concerned with disabled people provide a vast array of services. They conduct research leading to improved health and rehabilitation practices and techniques. They conduct and promote public and professional education programs in the causes, treatment and prevention of various disabling diseases. They establish training programs and performance standards for professional rehabilitation and other workers looking to achievement of the highest professional competency. They meet the special needs of certain disabled people, such as providing braille publications for people who are blind or teletypewriters for people who are deaf. They serve as advocates for disabled people in promoting the legislation and other action that is required to remove employment barriers, architectural and transportation barriers and the attitudinal barriers that prevent disabled people, in particular those who are severely handicapped, from leading full, productive lives. And, principally through the more than four thousand rehabilitation centers and workshops, the provide the restorative and rehabilitation services which disabled people often require to attain their full functional capacity.

These rehabilitation facilities are of many types. They include: the comprehensive rehabilitation center, the spinal cord injury center, the rehabilitation workshop, the vocation evaluation, and work adjustment center, community mental health centers, speech and hearing centers, optical aids clinics, halfway houses for the mentally ill and for the mentally retarded and the activity center. Some of the facilities are large; some, small. A single facility may serve all disability groups or only those in a selected disability category. Some are sponsored and operated by public agencies, but most are under voluntary auspices. Regardless of its size, sponsorship, program emphasis, or client population, each facility plays an important role in rehabilitation, particularly for the individual who is severely handicapped.

Rehabilitation facilities draw upon many disciplines for their services. The range of services which may be found in a facility is reflected in the Rehabilitation Act of 1973, which describes a rehabilitation facility as providing ". . . singly, or in combination, one or more of the following services for the handicapped individuals: (1) vocational rehabilitation services which include, under one management, medical, psychological, social and vocational services; (2) testing, fitting, or training in the use of prosthetic and orthetic

devices; (3) prevocational conditioning or recreational therapy; (4) physical and occupational therapy; (5) speech and hearing therapy; (6) psychological and social services; (7) evaluation of rehabilitation on potential; (8) personal and work adjustment; (9) vocational training; (10) evaluation or control of specific disabilities; (11) orientation and mobility services to the blind; and (12) extended employment for those handicapped individuals who cannot be readily absorbed in the competitive labor market." These services are rendered with the common objectives of assisting the handicapped individual to function at his maximum physical, personal and vocational level.

As in the past, the private voluntary organizations have a most significant role in all phases of activity essential to the well-being of disabled people. They work closely with the public agencies and are the principal suppliers of the professional services purchased by the public agencies for their clientele. They demonstrate new approaches in overcoming problems resulting from disability which are adapted and incorporated by the public agencies in their administrative practices. They train and supply the professional people needed in the public and private programs.

Often the private voluntary agencies, including the consumer organizations, receive public support for some phases of their activites. Continuing public support is essential to the survival of these voluntary agencies and to the continuation of the research and the unique activites which only they can carry out. With inflation and unemployment, private support of many voluntary agencies is diminishing. A critical issue, therefore, is continuation of public support to these private agencies in amounts which take cognizance of increased costs due to inflation and to diminishing voluntary support due to inflation and unemployment.

The Rehabilitation Research and Training Centers within various universities and medical centers have developed multidisciplinary programs designed to focus on high priority problems of persons with severe and/or multiple disabilities. The RT Centers conduct programs of research aimed toward the discovery of new knowledge which will improve rehabilitation methodology, management and service delivery systems; alleviace or stabilize handicapping conditions; and promote maximum physical, social and economic independence. They institute related teaching and training which will widely disseminate and promote the utilization of the new knowledge resulting from research findings, thereby reducing the usual long intervening delay between the discovery of the new knowledge which will improve rehabilitation methodology, management and service delivery systems; alleviate or stabilize handicapping conditions; and promote maximum physical, social and economic independence. They institute related teaching and training which will widely disseminate and promote the utilization of the new knowledge resulting from research findings, thereby reducing the usual long intervening delay between the discovery of the new knowledge and its wide application in practice; assist in preparing and increasing the number of research and other rehabilitation related professional and non-professional personnel where manpower shortages exist; and improve the skills of rehabilitation students, professionals, paraprofessionals, volunteers, consumers, parents and other persons involved in the rehabilitation process through the media of short and long term in-service and continuing education programs including seminars, workshops, course of study, conferences and demonstration—all for the ultimate purpose of favorably impacting and improving the effectiveness of those rehabilitation services that are assisting handicapped citizens to achieve the most productive life possible.

The range of research needs with respect to persons with severe disabilities is as broad and diverse as the problems and needs of the persons themselves. One way to summarize the range of research needs, and research contributions to solving problems, would be to highlight, across disability groups, the kinds of discoveries that have been made. For example, in medical research, the discovery of the Salk vaccine has significantly reduced the incidence rate of polio. The discovery of antibiotics have significantly increased the survival rate of paraplegics. In rehabilitation engineering research, the work on reading machines and mobility aids show great potential for assisting persons who are blind. Advances in telecommunications technology have broadened the social and vocational options that are open to many persons who are deaf.

While such a summary of research highlights the range of research contributions to each of the various groupings of persons generally

considered to have severe disabilities. such a summary lacks depth. Therefore. another way to summarize research contributions is to look in depth at one particular disability. e.g. spinal cord injury. and the broad range of investigative efforts that have been conducted. For example. spinal cord injury is a severe physical disability for which research has tackled knowledge gaps in physiological. psychological. biomedical. sexual. educational. vocational and many other areas.

Results of physiological research have provided the knowledge that now enables a person who breaks his back or neck to go through the acute medical phase of this disability free from decubitus ulcers (pressure sores) and urological complications (bladder infections). Research on the necessary elements for a successful rehabilitative phase have led to the development of the extremely cost effective spinal cord injury centers. Demonstration projects have documented the economic and social value of such one-stop spinal cord injury center at which the rehabilitation team includes all the professional specialties that can help the paraplegic avoid complications and return to society's mainstream as soon as possible.

Biomedical engineering research has led to development of environmental control devices for high-level quadriplegics. Thus, a person who can only use one muscle in his entire body can now operate a typewriter. telephone. tape recorder. microfilm reader. computer terminal. air conditioner. or virtually any device that can be controlled by simple electrical switches. Research and demonstration project in the area of housing alternatives for persons with spinal cord injury have accompanied efforts both to eliminate architectural barriers in all residences. as well as to expand the number of centers for independent living that provide quadriplegics who need personal care assistance, with the freedom of choice as to where to live. Research and training programs on sexual functining have helped to eliminate many of society's stereotypes (e.g. of the paraplegic as "half a man") and opened up new options for many persons with spinal cord injury and their significant others. Vocational rehabilitation research has established the wisdom of early referral, individualized case management. and open-ended, lifetime availability of services. Research on consumer involvement has uncovered a variety of methods by which a person with spinal cord injury or any disability, can have the major role in the planning. delivery and evaluation of medical, vocatinal. environmental and independent living rehabilitation services.

The above, very brief, research summary targeted at one disability group also lacks depth due to space limitations. Productive research related to spinal cord injury has been carried out in broad range of scientific and professional fields: from neurology and psychology to engineering and architecture.

The extent to which persons with severe disabilities are able to live independently and productively is constrained both by the limited accessibility of necessary service resources and by large gaps in the knowledge based upon which rehabilitative and other service efforts depend. The limited resources can be expanded if and when the public and the government make the humanitarian and economic commitment to providing both a minimum standard of living and an equal opportunity to all citizens. As Clark Abt observed in a recent report (Abt Associates: 1965-1975): "In the world of research and development, government social research funds are unusually limited and the problems addressed are extremely difficult. The federal government annually spends some $200 billion—half the federal budget—on social programs for health, education, welfare, employment, housing, crime control, etc., yet spends only about 1/4 of one percent—$500 million—on social research and development. Most growth industries—and government social programs are demonstrably a growth industry, having doubled every five years fro the last fifteen—spend from 5 to 10% of their annual revenues for R&D, much more than the 1/4 percent spent by the federal government."

The filling of the gaps in our knowledge base in order to better meet needs of persons with severe disabilities, depends to a great extent on fiscal resources to carry out necessary research.

Evaluation of Service Delivery Systems

Assessing the relevance of rehabilitation research, the consistency of services from area to area. the gaps in services from program to program or the evaluation of services from individual to individual is a difficult task. So many different factors (on which very little hard data exist) can influence such assessments. For

example, one can say that a low income quadriplegic gets better medical services in California or New York than in some other states with poor Medicaid coverage. One cany say a deaf person needing technical or college education is better off going to areas where there are reasonable programs (e.g. like Gallaudet College or the National Institute for the Deaf).

One can make many similar statements about other disabilities, programs and areas. But with hundreds of public and private programs in their current state of coordination, it is very difficult, particularly without systematically collected evaluative data, to make sound assessments.

One possibility for significant program evaluation that is recently receiving considerable attention is that of consumer evaluation of services. It seems obvious that the person with a severe disability frequently knows more about his wants and needs than the health care professionals around him. He or she is in the unique position, of all potential service-evaluation, to say whether the provided services met his or her needs. While society has long given "lip service" to the idea that people should have a voice in the decisions that affect their lives, recently a few health and rehabilitation providers have implemented the idea. For example, the Rehabilitation Act of 1973 puts emphasis of consumer involvement in the planning delivery and evaluation of rehabilitation services. An option for improving service delivery, then, is to involve consumers of service in evaluating the services provided and the service providers. For example, composite client ratings of rehabilitation counselor credibility and availability can be used as part of the agencies' performance appraisal of the counselor. Such measures of "client satisfaction" can be averaged across counselors to get measures of local area or regional VR office performance. Similar rating systems can involve persons with disabilities in evaluating other public and private agencies, and in assessing consistency and determining gaps in service.

There is another important issue regarding evaluation of services for the severely handicapped. Because of the nature of their disability, severely disabled persons may not be capable of achieving the same functional goals which we may set for the moderately or mildly handicapped person. This not to say that the more disabled are not capable of progressing toward a goal. *To the contrary*. For too long we have relegated many severely handicapped individuals to custodial treatment with little or no expectation of change. The point is that goals set for this target group should be tailored to the potential capacity of each individual and the attainment of such goals should be as highly valued as the attainment of more complex goals by higher functioning persons.

Attitudes Toward Individuals with Severe Handicaps

Individuals with severe handicaps are confronted by three distinct attitudes on the part of the general public which have a vital effect upon their livelihood, their well-being and their roles in society. These attitudes are indifference, discrimination and positive acceptance.

Indifference which is related to unawareness, uncertainty and apathy accounts for the lack of concern by the general public, communities and institutions about the continuation of the many man-made barriers that prevent severely handicapped people from achieving and enjoying the quality of life available to others in our society. As long as this indifference continues, severely handicapped people will be discriminated against in renting apartments, in securing employment, in securing credit and in having equal access to all aspects of our society. Many will also continue to be excluded from their home communities and placed in remote institutions due to a lack of commitment to develop services at the local level.

Correction of that indifference is basic to the removal of architectural barriers that prevent disabled people in wheelchairs and others from using public buildings, from entering places of employment, from using banks, department stores, restaurants, recreational centers and even from entering and leaving their apartments and homes. Correction of this indifference is also essential if the public transportation systems—buses, trains, planes, subway cars, which now are inaccessible to severely handicapped people are to be made accessible to them.

Community indifference is also responsible for the continued "dumping" of mentally disabled persons into remote state institutions. Though the numbers of persons residing in such facilities has declined, many severely handicapped are still excluded from their communities because of a lack of commitment to the development of services closer to home.

Sensitizing communities through public information programs on the nature of various disabilities and the needs and rights of the handicapped is essential to breaking down the attitudinal barriers that set apart handicapped people in the general public's mind.

Attitudinal barriers must also be reduced in order to allow access by the severely disabled to small group living arrangements in the community. Many of these home-like facilities are currently prohibited by zoning regulations from locating in residential communities.*

Disabled people themselves can contribute significantly to the modification of indifference. Advocacy groups within the local community, provision of information on the needs of the handicapped citizen, lobbying for the rights of accessibility to local facilities, and increased visibility of the handicapped, all offer two-way educational experience for both groups. Persistent pressure by handicapped individuals and their advocates in an organized manner can create change. The general public will learn to accept the presence of handicapped people in places of employment, education, commerce, entertainment, and recreation.†

Problems common to all persons with disabilities are frequently magnified for persons with severe disabilities. For example, discrimination in use of public and private facilities is a problem occasionally experienced by persons with a slight limp or thick glasses. But such discrimination is generally much more of a problem to a person with speech, mobility, and "cosmetic" difficulties as a result of cerebral palsy.

Architectural barriers, like a long flight of steps may be an inconvenience to someone using a cane, but they are an impossiblity to someone using a wheelchair.

The non-handicapped person may have little difficulty in securing housing in a residential neighborhood, but the development of small group living arrangements for the severely handicapped in such areas is frequently hampered by zoning and other restrictions. Thus the differences in the problems are not so much a difference in kind but a difference in degree.

*Valerie J. Bradley "The Severely Mentally Disordered," paper prepared for the National Institute of Mental Health.

†*Comprehensive Needs Study*–The Urban Institute, June 9, 1975 Report submitted to The Department of Health, Education and Welfare .

BARRIERS TO COMMUNITY LIFE

Efforts on behalf of severely handicapped persons have concentrated on restoration and rehabilitation to the highest level of independent functioning, especially toward the goal of self-support. For the severely handicapped, many of whom are not and may never be employable, this presents special difficulties. Self-concept and identity are established through major life roles and role relationships and the absence of work deprives one of a significant source of social validation. Without interaction in work, where most individuals achieve primary non-familial interaction, social isolation and a lessened self-concept can result.*

In a recent study, The Urban Institute attempted to measure the social interaction of severely handicapped persons by asking a number of questions relating to family and social life. Although an individual may live with family members, often the dependency created by disability affects self concept–this self-view is often diminished by the handicap. The handicapping condition distorts the perception of the individual's role within the family. Survey results substantiated the fact that although many handicapped persons have opportunities for social contacts, they may still be in a state of social isolation.†

Of the population sampled by The Urban Institute, 81 percent resided with family members and 65 percent of the sample had at least one relative living within 10 miles. Nonetheless, participation was quite limited. Respondents were asked about the kinds of social activites they had engaged in during the last *month.* The most frequently occuring activities were visiting with friends or family and shopping. Even with these activities, 33 percent had not gone outside their residence to visit family or friends, and 22 percent had not been visited in their homes by family or friends *even once* during the past month. Other social activities occurred even less frequently. In one month, 66 percent had not gone out to a movie, restaurant, or any other form of public entertainment; 80 percent had not attended PTA, lodge meetings, or other social or political group meetings; 93 percent had not done volunteer work; and 94 percent

*Report of the *Comprehensive Service Needs Study*, The Urban Institute, Washington, D.C.

†*Ibid.*

had not attended school or vocational training classes. Affiliation with other disabled people was infrequent. Only one out of ten of the individuals surveyed knew of any groups for the disabled, and only one out of ten respondents were members of such groups. Of these, only half ever attended meetings or had attended no more than once or twice a year.*

While these statistics provide a measurement of the kinds of social interaction and activities available to the respondents, they do not give an index of the quality of these social contacts and relationships as a factor in the reduction of boredom, loneliness, isolation, and feelings of helplessness and dependency.

In recent years, handicapped people, through consumer and advocacy groups have become more vocal in demanding equality in education, employment, housing and transportation. As a result, their integration into the mainstream of life and fuller participation in all activities of living is more a reality today than it was 25 years ago. For example, with the development of special education programs for handicapped children and the growing emphasis on placing these children in regular shcool systems, today's handicapped children are being given greater opportuniteis for developmental experiences. The move in recent years to reduce the use of institutional care for the mentally disabled in favor of community-based services has made it possible for many such persons to remain in the community.

Many adult handicapped persons have been deprived of daily life experiences by physical limitations, inadequate schooling, institutionalization, experiences by physical limitations, inadequate schooling, institutionalization, parental overprotection, and limited social opportunities. This deprivation can lead to an inadequate personality development, passivity, dependence out of proportion to the degree of disability, and isolation. Social or recreatinal programs can alleviate some of these deficiencies to a degree and provide social interaction and development experience which may have been totally or partially lacking in earlier years.† Resocialization programs which focus on the development of "coping" skills needed in every day living are also valuable for persons who have been isolated in institutions.

Because of the limited extent of social integration of the most severely handicapped in particular, they may require compensatory kinds of services. The ideal should be wholly integrated and accessible facilities for all. However, a need exists for programs and facilities to provide special opportunities to those handicapped persons who lack the skills necessary to be integrated into routine programming. Special activities could be planned and designed in much the same manner as community-based programs for the elderly: community centers, self-help organizations, activities, and transportation. Experiences would be provided to offer the disabled an opportunity to discover areas of competency and grow away from isolation and total dependency. The development of new skills and interests would provide transitional experiences and orientation, working toward social adjustment and inclusion in regular community programming.*

Attitudinal, architectural and transportation barriers also prevent handicapped people from receiving their fair share of community sponsored social, cultural and recreational services. These and other deterrents must be removed if disabled people are to enjoy as a fundamental human and civic right full participation in the social and cultural aspects of our society.

TRANSPORTATION BARRIERS

Transportation is a vital element in the independence of severely handicapped people. The ability of most severely handicapped persons to get medical care, rehabilitation education, employment, and recreation depends upon their ability to get from their homes to other places. When, because of their own limitations or obstacles in the transportation environment, they cannot reach those places, their potential for improved functioning may be significantly reduced. Access to the public transportation systems for those severely handicapped who are mobile has long been denied, more because of the nature of those systems than to the nature of the individual's handicap. Congress recognized the need to improve the mobility of those

*Report of the *Comprehensive Service Needs Study*, The Urban Institute, Washington, D.C.
†*Ibid.*

*Report of the *Comprehensive Needs Study*, The Urban Institute, Washington, D.C.

with limitations when it enacted the Urban Mass Transportation Act, which stated that "... handicapped persons have the same right as other persons to utilize mass transportation facilities and services..."

The physically handicapped—i.e., those people in wheelchairs and those using canes and other special equipment—face a series of architectural and attitudinal barriers that make transportation on existing systems very difficult or impossible. Steps, narrow doorways, and inaccessible facilities and vehicles are all fairly well-known transportation problems. Significant but less well known problems include discriminatory practices by insurance companies with regard to disabled automobile drivers. Many instances are reported of these drivers being placed in an assigned risk category (where they pay higher rates) when there is no empirical evidence that they are poorer risks. In fact, the available evidence suggests the opposite. Considerable press attention has focused on discrimination by airlines in refusing to fly disabled passengers without a medical certificate or attendant.

Other barriers prevent people who are physically disabled from using transit systems that have been thought to be well suited to their needs, such as BART, the Bay Area Rapid Transit System in San Francisco. Problems that the handicapped face on BART include: difficulties in using the telephones needed to gain access to the elevators at the stations; lack of secure, out-of-the-way places where people in wheelchairs can wait; and gaps between the loading platforms and passenger cars that can entrap a cane, crutch, or wheelchair tire. These situations are not as obvious as the presence of steps or narrow doors but can present as much difficulty to many of the transportation-handicapped. The more subtle aspects of transportation handicaps go beyond the system itself. One reason for less than the anticipated use of BART is not BART per se, but the fact that there are curbs a block away from a stop.*

Attitudinal barriers cause transportation handicaps for others besides those with obvious disabilities. Some persons with epilepsy experiencing petit mal seizures on buses and trains, for example, have reported that they have been treated with understanding by bus drivers and other transit personnel. For those who have not received such treatment, however, riding mass transit facilities can cause emotional difficulties. It can also be expensive if the person with epilepsy is forced to leave the scene of the seizure in an ambulance and be charged $50 for the trip.*

The deaf, blind, and mentally disabled constitute a large percentage of the transportation handicapped, and each group has unique problems. Deaf people cannot hear arrival and departure announcements at airports and train or bus stations. The boarding of trains can also be a diffcult process for the deaf, since there are often no signs directing people to the appropriate cars. Possible solutions for this group, then, include large and more numerous video screens at mass transit facilities giving current information on arrivals, departures, and delays.†

Blind people have almost the opposite problem in using mass transit facilities. They need frequent travel and departure announcements at each facility. Passengers who are blind would benefit from announcements given during trips on buses and trains identifying particular streets and stations. Those who are blind and partially sighted waiting at bus stops would also benefit from announcements from the driver giving route designation and destination. Route timetables in braille and relief maps in stations would greatly assist the blind in using mass transit facilities.‡

The mentally disabled have special problems in using mass transit facilities. Complicated routes and schedules often are beyond their comprehension. Persons who have been institutionalized for long periods of time are often frightened or confused by these complexities. In addition to travel training, the mentally disabled could use color-coded bus identification markers, simplified route schedules showing principal routes and assistance in route planning. In addition to problems with public transportation, many persons who have been institutionalized are denied driver's licenses by some state laws.

The effects of medication contribute to the travel difficulties of some handicapped persons. For example, persons receiving kidney dialysis

*Report of the *Comprehensive Service Needs Study*—The Urban Institute, Washington, D.C.

*Report of the *Comprehensive Needs Study*, The Urban Institute Washington, D.C.

†*Ibid.*

‡*Ibid.*

take medication which often has the side effect of making them dizzy. Although their mobility may be rated as high, they cannot drive because of the dizziness. Furthermore, many cannot stand in line for any period of time. This makes use of public transportation very difficult, since most bus stops do not have seating facilities and most buses do not have reserved seating arrangements. This group, then, may require special transportation arrangements, such as dial-a-ride vans or taxis, that can reduce their waiting time.*

A wide range of alternative solutions is available from inexpensive capital-intensive modifications of existing transportation systems to the building of a wholly new transportation system to accommodate the severely handicapped. Mobility training is valuable to individuals with certain disabilities. Curb modifications; automobile modifications; retrofitting bus or surface rail systems with a ramp or power lift, seating space and tie downs for wheelchairs, driver-training sensitivity to the needs of the transportation handicapped would be helpful alterations. Regardless of the modifications made to fixed-route transit systems, there will always be some handicapped persons who require door-to-door service such as taxicabs, "handicabs", and dial-a-ride. Direct subsidies such as income tax credit might assist with the extra costs.

Clearly, there are both economic and non-economic benefits in improved mobility. Many handicapped persons would be newly able to work, study, and participate in recreational activities. Other benefits include the reduced burden of the handicapped on friends and relatives and other caretakers and the increased contribution to the community through the activities of many talented and well-educated handicapped persons. Also of benefit would be the reduction of emotional burdens of physical problems on individuals and the entire community, which are often debilitating and inhibit productivity.†

The psychological benefits to the handicapped individual are also important to consider. The opportunity for increased mobility, if utilized, necessarily increases the amount and variety of social contacts, and these contacts are likely to improve performance in various roles and to enhance self-concept.

The transportation needs of the severely handicapped are an important element in any program which seeks to make this group more independent and productive. Yet finding solutions to their transportation problems is a complex undertaking, since different types of severely handicapped individuals require different kinds of transportation. It is important, then, that a wide range of solutions be explored and evaluated so that the most effective national program options are developed.*

ARCHITECTURAL BARRIERS

Architectural barriers are the manmade features of buildings and facilities which impede or preclude their use by handicapped people, or which impede the conduct of effective and responsive programs.

These features of factories, businesses, parks, theaters, restaurants, beaches, apartments, etc. exist because in the design and planning the needs of handicapped citizens are not considered. These barriers reflect the indifference and lack of awareness by architects, urban planners, builders, and local officials in the design and construction of facilities and effectively deny handicapped people the right to work, travel and recreation. Incentives to create a barrier-free environment and to ameliorate the conditions which exist for the handicapped individual in using private facilities have yet to be addressed.

Architectural barriers affect all aspects of living and all ages of the severely handicapped; for example, the layout of a kitchen and its equipment which makes it difficult and sometimes impossible for a handicapped housewife to carry out her homemaking responsibilities; the thoughtlessly designed school and playground which makes it necessary for the young to be educated separately and lose contact with friends; steps which prevent an older woman with arthritis from going to her church for the spiritual and social satisfaction it gave her when she was able-bodied.

The Comprehensive Needs Study's survey of providers of rehabilitation services asked respondents to indicate to what extent that certain

*Report of the *Comprehensive Service Needs Study*–The Urban Institute, Washington, D.C.
†*Ibid.*

*Report of the *Comprehensive Service Needs Study*–The Urban Institute, Washington, D.C.

services would effectively assist severely handicapped persons in rehabilitation in independent living programs. Almost all of these providers (96 percent) agreed that home modifications would be important. However, only 5 percent of such respondents were actually engaged in providing home modification services. In the same survey, 89 percent of the rehabilitation providers agreed that "lack of barrier-free housing" was a significant problem for the severely handicapped. Only two other problems on the list of potential impediments were agreed to by a higher percentage of providers. Interestingly, both of those were also barrier problems—"lack of barrier-free employment settings" (90 percent) and "lack of usable transportation" (93 percent).

Public Law 90-480, the Architectural Barriers Act of 1968, requires that all Federal structures as well as those financially assisted with Federal funds be made accessible to the handicapped. The law also stipulates that when public structures undergo extensive alterations, the elimination of barriers shall be included as part of the work. Among the barriers to be modified are stairs, elevator buttons, narrow doorways, revolving doors.

The provisions of P.L. 90-480 as amended by P.L. 91-205, appear to be weakly enforced partly because some of its language permits large loopholes. In addition, the law is primarily relevant to Federal buildings, while the bulk of public buildings are State and local structures. However, it is now generally recognized that the biggest problem area with respect to architectural barrier laws is that of compliance.

Section 502 of the Rehabilitation Act of 1973 created the Architectural and Transportation Barriers Compliance Board. A major purpose of the Board is to insure compliance with Public Laws mandating accessibility and usability of the man-made environment by the handicapped and elderly. Many of the handicapped look to the Board with great expectation that its potential for enforcement of compliance requirements will be fulfilled.

Almost all states have passed laws or taken official action with respect to the elimination or removal of barriers, but here again, action is often vague or weak and in only a few states do the laws apply to privately constructed buildings and facilities.*

*A Survey of State Laws to Remove Barriers, the President's Committee on Employment of the Handicapped, Washington, D.C.

Rehabilitation agencies, public and private, consumer organizations and other state, county and municipal organizations need to take strong advocacy roles for adequate legislation and other action to bring about barrier-free buildings and facilities, including housing. In addition, it would be of help to many severely disabled individuals to have a local program giving information on how modifications could be made and on types of devices which assist in performing various household functions. Such a program could include assistance in finding barrier-free housing. Since the bulk of the costs of architectural modifications is now absorbed by individuals or families, many in the low income brackets, some sort of financial assistance should also be considered.

On the broader level, greater enforcement of existing standards for a barrier-free environment would do much to assist the most severely handicapped. Without accessible homes, offices, and public buildings and areas, the probability of the severely handicapped achieving the better quality of life envisioned in the act establishing the White House Conference on Handicapped Individuals will be low.

Another more intangible architectural barrier which confronts the severely disabled is the institutional and forboding nature of the structures in which many of the more handicapped are forced to exist (i.e., state hospitals, nursing homes, etc.). Such structures are inhospitable and counter therapeutic and reinforce the separateness and isolation of those within—the lack of resemblance to more normal settings also contributes to the stigma attached to the severely disabled and the community's indifference.

GEOGRAPHIC MOBILITY

Geographic mobility, the ability to move one's place of residence to somewhere beyond a given labor market, is often necessary to gain access to specialized jobs and educational opportunities, to escape labor surplus areas, to move along the career ladders of large organizations, or to meet a variety of personal and family needs. Inability to move, especially at the age of career development and family formation, can drastically restrict one's life opportunities. Thus there is an increasing recognition of the social value of relocation assistance. The United States is now the only major Western nation that does

not use some form of relocation assistance to alleviate regional unemployment.*

Many individuals who are most severely handicapped have additional reasons to move. They may require or might benefit from conditions which exist in only a few locations, such as special medical, therapeutic, or educational services, sheltered workshops, and jobs or schools suited to their individual qualifications and disabilities. They may seek a supportive social situation and a safer, more accessible physical environment with such aids to independent living as are being created by and for the physically handicapped in cities such as Berkeley, California. Berkeley's Center for Independent Living (CIL) for example, in the San Francisco-Oakland metropolitan area, benefits strongly from the existence of such services as Neighborhood Legal Assistance, the manufacture, sales and repair of orthopedic supplies, a pool of potential attendants and readers, a university, and the regional headquarters of various agencies and service organizations where client requests are presented. In a smaller or regionally less significant metropolitan area, many of these features would have to be provided internally at considerable cost or would simply be unavailable.

Efforts to enhance the mobility of the most severely handicapped are likely to appeal most to certain subgroups: the better educated, especially those in their early twenties and those without (or willing to leave) family ties, those of retirement age with substantial assets or pensions, and young children who are themselves severely handicapped or are dependents of handicapped persons. These subgroups are the ones who would be most likely to move spontaneously if they were not handicapped.†

People who are severely handicapped are frequently unable to change their locations because they lack the funds and resources with which to do so. One method of improving their geographic mobility would be to establish major pilot projects incorporating both information and direct services. Such projects would contribute in the following ways to any long-term mobility program subsequently adopted:

1. They would generate information on patterns of demand, including the aggregate density of response from a pilot area, and the composition of demands for different kinds of services by different users.
2. They would permit the working out of cost-effective methods and procedures suitable for replication and the elimination of costly or unacceptable features.
3. They would generate more accurate cost data.
4. They would generate a trained, experienced group of potential program administrators.

Another method is to extend research into the actual mobility patterns and mobility needs of the severely handicapped. Also needed is a geographic analysis of the accessibility of present and projected services to the national severely handicapped population. Finally, survey information on mobility and locational preference of the handicapped is needed. This information, when combined with ongoing experience of the pilot program should provide material for legislative consideration.*

REHABILITATION–SELF-CARE AND VOCATIONAL OBJECTIVES

Goals of Rehabilitation

Rehabilitation has the objective of providing services for the disabled individual that will help each such person achieve the fullest potentialities for whatever satisfactions that person wants in life, and is able to attain. By providing help toward improvement of functioning and/or restoration of capacity, it is an important means for increasing independence, dignity, and self-respect. At one end, the maximum attainable goal may be progress from bed to wheelchair or an increased capacity for self-care. At the other extreme, it may be aimed at restoration to paid employment. The former is often designated as "rehabilitation for independent living"; the latter is designated as "vocational rehabilitation."

Among the 10,000,000 severely disabled individuals in the United States today, most are dependent on others for their support or for

*Report of the *Comprehensive Service Needs Study*–The Urban Institute, Washington, D.C.
†*Ibid.*

*Report of the *Comprehensive Needs Study*. The Urban Institute, Washington, D.C.

assistance in activities of daily living. If they were provided modern rehabilitation services, millions could live their lives in greater independence and with greater dignity. Many of these could return to work, or work for the first time. Others could learn self-care. In either case, the beneifts from rehabilitation services would extend not only to the disabled persons alone, but to their families and to society as a whole. For those who return to work lost wages would be restored, industry would regain labor skills, and there would be new purchasing power and tax revenues in the economy. For those who were freed from constant attendance or dependency, institutional, disability, income and welfare costs would often be decreased.

Self Care

It is not possible to estimate with any exactitude the number of severely disabled people who could benefit from rehabilitation services which would enable them to meet, without assistance, the normal demands of daily living—dressing themselves, feeding themselves, taking care of their other personal needs—and participating in family and community activities. It is reasonable to assume that they number in the millions. They are among the two million Americans who are homebound—the two million people who are "so limited by reason of the severity of their physical, emotional, intellectual and environmental disabilities that they cannot regularly leave their homes with the transportation normally available to them to participate in community-based employment social and educational activities".* They are among the four million people with severe disabilities who are 65 years of age and over, many of whom are in nursing homes. And they are among the almost two million of all ages who are in institutions, many of whom are young people. Very substantial numbers of these people could achieve either full or a greater degree of independence in meeting their daily living needs and in engaging in community and social activities if they were given the opportunity to receive rehabilitation services, attendant care and suitable housing.

There is no single nation-wide State-Federal program which provides rehabilitation services to severely disabled people to enable them to achieve independence in meeting the normal demands of daily living. Such rehabilitation services that are provided for this purpose are provided, as a rule, through rehabilitation centers. Sometimes they are included in institutional programs; sometimes they will be found in hospital programs; sometimes they will be found in homes for the aged or nursing homes. Occasionally, there are community programs which bring these services to the disabled individual in his home. Most often the absence of such rehabilitation programs and services in our communities is the rule rather than the exception.

A critical issue is how to establish programs throughout the country that will assure the provision of rehabilitation services for independent living purposes to the millions of severely disabled people who could benefit from such services.

Vocational Objectives

It has been demonstrated in thousands of individual instances that severely disabled people, regardless of the severity of their disabilities, can compete with their able-bodied peers in all of the professions, in industry, in commerce, in government—in fact in every work situation in our society. And yet, they are unemployed in far larger numbers proportionately than non-handicapped people. Where a certain occupation might be considered as suitable entry jobs for a young able-bodied person starting a working career, these are often terminal jobs for people who are severely disabled. While vast amounts of money—in the thousands of millions of dollars are spent on professional, vocational and other career training, severely disabled people benefit very little because the facilities are inaccessible, transportation unavailable and the few modifications required to accommodate their conditions are lacking.

Millions of severely disabled people could compete on equal basis with their able-bodied peers for positions in the competitive labor market if they could obtain the rehabilitation services which they need through programs designed to reach them in their homes, in institutions, or which otherwise made the rehabilitation services readily accessible and available. The models for such programs are well known and their validity established. For example, through one such model people severely

*_Homebound Rehabilitation: Preparing the Way_, Journal of Rehabilitation, Sept./Oct. 1975.

disabled and confined to their homes (by rheumatoid arthritis, muscular dystrophy, cerebral palsy, multiple sclerosis, rheumatic heart disease, paraplegia and quadriplegia from spinal cord injuries) are earning substantial wages, many outside their homes, in the information industry as computer programmers, microfilmers, data entry operators, inspectors and in other related occupations and skills.

The techniques for establishing severely disabled people in these and in hundreds of other occupations in competitive industry are known. What is lacking and urgently needed are the resources with which to establish these special programs in all communities throughout the nation. What is also needed is vigorous enforcement of existing anti-discrimination legislation, particularly sections 501, 503 and 504 of the Rehabilitation Act of 1973, as amended which pertain, respectively, to employment of handicapped individuals in government, employment of handicapped individuals by employers under Federal contracts and to the prohibition of discrimination against handicapped people in any program or activity receiving Federal financial assistance.

There are some severely disabled people for whom placement in competitive industry is not feasible. These people need and can function well in sheltered work situations. For example, there are 30,000 to 40,000 blind persons in the United States who could benefit from sheltered workshop services.* Many of these people in addition to being blind have been further disabled by cerebrovascular and cardiovascular accidents, cerebral palsy, mental retardation, mental or emotional illness, deafness or severe hearing loss, diabetes, orthopedic disorders including amputations, tuberculosis, alcoholism, drug addiction, and other disorders. Only about 5,000 such blind individuals are currently receiving the rehabilitation and employment services which the sheltered workshops have to offer, and these blind people are principally in the 87 workshops (in 36 states) affiliated with the National Industries for the Blind. Workshops for the blind, like those for other disabled people, have been supported over the years through voluntary contributions and philanthropic bequests. They have been strained to their financial limits and cannot, without direct public support, meet current needs. Sheltered employment both in special workshops and in competitive areas needs to be developed for many individuals who are mentally retarded. It is estimated that there are at least 400,000 retarded persons living in the community who have the potential to work, but who are now unemployed. There are other individuals with single or multiple severe disabilities who need work under sheltered conditions—an amputee with a heart condition for example.

Many severely handicapped persons currently employed part-time or unemployed, could be employed in the competitive economy if sheltered work tailored to their capacities were developed in the competitive work environment. The few demonstrations that have been developed suggest that assisting an employer in designing the appropriate work environment is potentially very effective. Under such a program, the employer would be paid by the government the difference between the value of the worker's product and the minimum wage or paid a fixed percentage for certain kinds of employed severely handicapped people.

In order for sheltered workshops to pay a minimum wage to workshop employees, government wage supplements would be necessary for eligible employees. In addition, consideration would need to be given to legislation and support providing for unemployment compensation, Social Security, and health insurance coverage for all employees in all sheltered workshops, as well as inclusion of workshops within the National Labor Relations Act. Also, there is need to consider amending the Social Security Act so that Disability Insurance and Supplemental Security Income payments are not affected by earnings in sheltered workshops or in competitive employment until earnins exceed a level that provides an incentive for rehabilitation. Of equal importance is continuation of health coverage under Medicare or Medicaid for the beneficiary who is rehabilitated until such time as adequate health coverage under another program is provided.

Should a public works program be established to cope with the current unemployment situation, adequate provision should be made to assure that disabled people including the severely disabled are employed. A public works program could also provide employment for able-bodied persons as readers, interpreters, and

*Harold Richterman, *Services to the Blind: A Community Concern*, Eleventh Institute on Rehabilitation Services. (DHEW).

attendants, thus increasing the support personnel needed to facilitate independent living.

Advocacy and Continuity of Attention

Because many severely disabled persons have a handicap which will last for a protracted period of time or perhaps for their lifetime, there is a critical need for a mechanism which assures continuity of attention for the course of the disability. The severely disabled have a constellation of needs ranging from residential, medical, legal, social, to rehabilitation. Though services to meet these needs may be available from a variety of different agencies, most severely handicapped are unable to "negotiate" the complex bureaucratic structure which is responsible for determining eligiblity and delivering service.

A system of case management is needed to:

1. assure that the disabled person receives his or her needs;
2. prepare a comprehensive plan of services tailored to the individual needs of the severely handicapped person;
3. monitor the quality of services provided to insure their continued appropriateness and effectiveness

No one agency is currently accountable for this ongoing attention and continuity. It is well known that in the absence of such continuity, many of the severely disabled will "fall between the cracks" and will be denied those services which may be crucial to their continued growth and rehabilitation.

In addition to case management—and perhaps as a part of such a system—there is a need for aggressive advocacy on behalf of the legal and human rights of severely disabled persons. Though many individuals are perfectly capable of speaking for themselves, others—because of mental disability, fear, or lack of knowledge—are unable to secure their rightful entitlements.

Recently, this advocacy has taken the form of litigation to secure rights to education, treatment and protection from harm for persons who have been previously abused, ignored, and discriminated against. Advocacy can also be provided by volunteers at the community level who work in close contact with the severely disabled and assist them in securing services and other entitlements. Some states have established advocacy programs which may either rely on legal or administrative intervention on behalf of the severely disabled.

All of these approaches are directed to one end—increasing the visibility of the problems encountered by the severely disabled and prodding public agencies to respond to such problems.

APPENDIX A

ESTIMATES OF SEVERELY DISABLED POPULATION

1. The Arthritis Foundation: "Arthritis is America's number one crippling disease. Nearly 3.5 million persons are estimated to be disabled by this disease. (1969-1970 Household Interview Survey conducted by the U.S. Public Health Survey.) Some 730,000 persons either require assistance in getting around or are confined to their houses. (Chronic Conditions and Limitations of Activity and Mobility 1965-1967, Vital Health Statistics Series 10, Number 61, HEW)."

2. National Association of the Deaf: "Data available to the NAD indicates an overall deaf population of about two million. About 400,000 are in need of rehabilitation services. Over 100,000 must be considered to be severely disabled."

Professional Rehabilitation Workers With the Adult Deaf: "According to the recent National Census of the Deaf Population (NCDP), carried out from 1970 through 1973, severely disabling prevocational deafness has a prevalence rate in the United States of 2 per 1,000 or, more precisely, 203 per 100,000 population. This rate is *twice* the previously estimated rate on which rehabilitation services for deaf people have been based. Even more revealing is the fact that the 6-to-16-year-old category contains severely disabled prevocationally deaf persons at a rate 38 percent *greater* than the 25-44-year-old group and 13 percent greater than the 17-24-year-old group, so that even if the general population remains constant, the proportion requiring special services will grow rapidly."

3. United Cerebral Palsy Associations: In a survey of a sample geographical area with a population of 22-1/2 million, "There are approximately 8,250 who need or could use some community based services." In the total population of the United States the number would be about 80,000 persons. These data do not include those under age 21 and those in institutions.

4. International Committee Against Mental Illness: "There is no really hard data as to the number of persons—in terms of either incidence or prevalence—encompassed within the major categories of mental disorders. Such data as exists are usually extrapolations of limited and usually unrepresentative epidemiological studies in specific communities, for example, the Midtown Manhattan Study, or are based on standard institutional reports from a number of federal and state agencies giving statistics on admissions, readmissions, discharges, etc. from such facilities as Veterans Administration hospitals, state and county mental hospital, private psychiatric facilities, community mental health centers, psychiatric departments of general hospitals, outpatient clinics, and similar service units. . . . Judgements as to service needs and anticipated functional capacity of the physically disabled—the blind, deaf, paraplegics, etc.—although taking into account the derivative psychological concommitants of such disabilities—are generally less complex than parallel judgements required to be made for the psychiatrically disabled. . . . Mixed impairments, i.e., alcoholism and mental disorder, drug abuse and mental disorder, further complicate the problems of developing effective and appropriate means of rehabilitative intervention."

The National Association for Mental Health: "How many people are we talking about? We don't know. The services are disconnected, and control dispersed; there is no uniform reporting system. Furthermore, their impact on society is far in excess of their numbers. Witness the recent statewide scandals in New York and California. Many receive attention only from the police, courts and correctional systems. The 1957 Commission on Chronic Illness reported 109 in every 1,000 people have a mental disorder, 49% of the people entering state mental hospitals have been there at least once before. The more often patients have been admitted to a mental hospital, the more likely they are to return in the future. The National Center for Health Statistics reports that 10% of the people with chronic conditions are unable to carry out major activities due to mental problems. The National Institute of Mental Health Biometry Branch is currently conducting a study on chronically mentally ill people."

5. Epilepsy Foundation of America: "The National Institute of Neurological Diseases and Stroke estimates the number of epilepsy-affected persons in the U.S. to be between 2 and 4 million, a prevalence rate of between 1 and 2% . . . for each patient with epilepsy who seeks medical care, there are others who go undiagnosed and still others who hide their disorder. . . . "It has been estimated that there are currently 1,157,300 children under fourteen in the epilepsy population of the United States . . . with an expected 1970-1980 increase of 446,000 patients in this age group. . . . "Fifteen to twenty percent of the epilepsy population (have) seizures (which) cannot be controlled by currently available methods."

6. Muscular Dystrophy Associations of America: "Over 200,000 men, women and children from all walks of life are severely crippled because of progressive muscular dystrophy and related muscular disorders."

7. The Easter Seal Society: "It is estimated that at least 500,000 people in the United States now have multiple sclerosis and related diseases."

8. Cystic Fibrosis Foundation: "While it is difficult to document incidence and prevalence, since the disease is not reportable and because its manifestations are often mistaken for those of other disorders, there are believed to be approximately 40,000 individuals with cystic fibrosis . . . incidence is estimated at one in every 1,500 live births."

9. National Association for Retarded Citizens: "Using the 3% prevalence of mental retardation, we would estimate that there are 6,100,000 mentally retarded persons in the United States. We further estimate that 89% of 5,500,000 fall within the mild and moderate ranges of mental retardation. Thus, we can assume that 5,500,000 mentally retarded persons are in need of a vast array of services. Included among these services is the need for vocational training and employment opportunities."

"According to definitions in the Rehabilitation Act of 1973, all mentally retarded persons would be considered 'severely disabled.' With

regard to our own definition, we would estimate that approximately 11% of the mentally retarded persons in the United States fall within the severe and profound ranges of mental retardation. Thus, 671,000 mentally retarded persons would, using our own definition, be classified as 'severely disabled.' "

10. The National Society for the Prevention of Blindness estimates that there are approximately 475,200 blind persons in the United States today and that 34,000 persons lose their sight each year. The National Center for Health Statistics estimates the number of persons with severe visual limitations at about 1,000,000 throughout the country. It is also estimated that nearly half the U.S. population suffers from a visual disability that require corrective lenses.

It is generally agreed that in the "blind" and "severe visual limitations" group, more than 50 percent and perhaps in excess of 60 percent are 60 years of age and older.

APPENDIX B

INDEX OF AGENCIES SERVING HANDICAPPED INDIVIDUALS

Federal Agencies in DHEW

NAME OF AGENCY	Relationship to Persons Who are Handicapped		
	PRIME	SECONDARY	SAME AS OTHERS
Mental Retardation Program	X		
Center for Studies of Schizophrenia	X		
Division of Mental Health Serv. Programs			X
Mental Health Serv. Dev. Branch			X
Comm. Mental Health Servs. Support Br.			X
Maternal & Child Health Serv./PHS			X
Crippled Children's Services/PHS	X		
Maternity & Infant Care Prog./PHS	X		
Family Planning Programs/PHS		X	
National Health Serv. Corps./PHS			X
Community Health Services/PHS			X
Migrant Health Program/PHS			X
Health Maintenance Organizations/PHS			X
Maternal & Child Hlth. Research/PHS			X
Maternal & Child Hlts. Training/PHS			X
Indian Health Services/PHS	X		
Indian Health Facilities/PHS	X		
Div. of Hospitals & Clinics/PHS			X
Div. of Fed. Emp. Health			X
Bureau of Prisons Med. Prog./PHS			X
Handicapped Research & Demon./OE-BEH	X		
Handicapped Innovative Prog. Deaf-Blind Center/OE-BEH	X		
Handicapped Early Childhood Ass./OE-BEH	X		
HC P.E. & Rec. Research	X		
HC P.E. & Rec. Training	X		
HC Preschool & School Programs	X		
HC Regional Resource Centers	X		
HC Teacher Education	X		

Federal Agencies in DHEW (Continued)

NAME OF AGENCY	Relationship to Persons Who are Handicapped		
	PRIME	SECONDARY	SAME AS OTHERS
HC Teacher Recruitment & Info.	X		
Spec. Prog. for Children with SLD	X		
Regional Education Programs	X		
HC Media Services & Capt. Films	X		
Severely Handicapped Projects	X		
Basic Grants to States for Voc. Tech. Educ./)E-BOAE	X		
Project Head Start/OCD		X	
Office of Veterans Affairs/OHD			X
Office of Volunteer Dev./OHD			X
Architectural & Trans. Bar. Com. Board/OHD	X		
Admin. on Aging/OHD			X
Grants for St. & Comm. Prog. on Aging			X
Office of Planning & Eval.			X
Nutrition Prog. for the Elderly			X
Nursing Home Interests Staff			X
Off. of Native American Programs			X
Rehab. Basic Support Program/OHD	X		
Spec. Proj. for the Severely HC	X		
Spec. Fed. Resp. Fac. Imp. Grants	X		
Basic Support Program-Construction & Establishment of Rehab. Fac.	X		
Spec. Fed. Responsibilities-Construction of R/F	X		
Special Fed. Resp.-Initial Staffing Grants	X		
Voc. Training Services Grants	X		
Spec. Fed. Resp.-Project Dev. Grants	X		
Spec. Proj. & Demon.–Tech. Assistance	X		
Projects with Industry	X		
Sheltered Workshop Study	X		
Comp. Social Rehab. Research	X		
Randolph-Sheppard Vending Fac. Prog.	X		
Rehabilitation Training	X		
Dev. Dis. Spec. Proj. (Hosp. Imp. & VR)	X		
DDD Univ. Aff. Fac. Demon. & Training	X		
Developmental Dis. Formula Grant Prog.	X		
Medicaid/SRS-MSA			X
Public Assistance-Social Serv./SRS-CSA	X		
Assistance Payments Adm.			X
Office of New Programs/OCR-OS	X		
Disability Ins. Prog./Soc. Sec. Adm.	X		
Office for Handicapped Individuals	X		

NAME OF AGENCY	Relationship to Persons Who Are Handicapped		
	PRIME	SECONDARY	SAME AS OTHERS
Community Services Administration			
Community Action Agencies			X
Veterans Administration			
Selective Placement Program	X		
Audiology and Speech Pathology	X		
Blind Rehabilitation Program	X		
Prosthetic and Sensory Aids	X		
Multidisciplinary, Multifaceted Program of Mental Health	X		
Spinal Cord Injury Service	X		
Pension for Non-Service Connected Disability for Veterans	X		
Adaptive Equipment	X		
Specially Adapted Housing for Disabled Veterans	X		
Compensation for Service Connected Disability	X		
VA Vocation Rehabilitation	X		
Veterans Housing: Direct Loans for Disabled Veterans	X		
War Orphans and Widows Educational Assistance	X		
Four other VA programs			X
ACTION			
Foster Grandparent Program			X
Retired Senior Volunteer Program			X
Senior Companion Program			X
SCORE/ACE			X
Volunteers in Service to American (VISTA)			X
General Services Administration			
Purchase of Products and Services of the Blind & Other Severely Handicapped	X		
Personal Property Donations			X
Disposal of Suplus Real Property for Health & Education Purposes			X
Concession Stands for the Blind	X		
Removal of Architectural Barriers	X		
National Aeronautics and Space Administration Medical and Health Related Research & Development		X	
Occupational Safety and Health Review Commission			X
Small Business Administration			
Handicapped Assistance Loan Program (HAL-1)	X		
Handicapped Assistance Loan Program (HAL-2)	X		

Independent Agencies (Continued)

NAME OF AGENCY	Relationship to Persons Who are Handicapped		
	PRIME	SECONDARY	SAME AS OTHERS
Economic Opportunity Loans			X
Regular Business Loans			X
U.S. Civil Service Commission			
Office of Selective Placement Programs	X		
Interagency Committee on Handicapped Employees	X		
Personnel Research & Development Center	X		

Other Federal Departments

NAME OF AGENCY	Relationship to Persons Who Are Handicapped		
	PRIME	SECONDARY	SAME AS OTHERS
Dept. of Agri.-Extension Serv.	X		
Dept. of Commerce			
Natl. Tech. Unf. S.		X	
Soc. & Econ. Statistics Admin.		X	
Econ. Devel. Admin.			X
Dept. of HUD			
Direct Loan Program for the Elderly & Handicapped	X		
Special User Research/0/R&D-HUD			X
10 Other HUD Programs			X
Dept. of Interior			
Bur. of Indian Affairs/O. of Educ. Prog.	X		
Dept. of Labor			
Off. of Veterans Re-emp. Rights			X
Bureau of Apprenticeship & Training			X
USES-Ser. To H&D Veterans	X		
Emp. Stand. for Handicapped Wkrs.	X		
Off. of Wkrs. Comp. Prog.-Fed. Emp.	X		
Off. of Wkrs. Comp. Prog. Longshore & Harbor Workers	X		
Off. of Wkrs. Comp. Prog. Div. of Coal Mine Wkrs. Comp.	X		
Off. of PD & Acctabil-for S/Wkshp. Spec. Wage Standards	X		
Sub-Min. Wage Cert. of HW	X		
Emp. Standards Adm. Woman's Bur. Fair Labor Standards Act			X

Other Federal Departments (Continued)

NAME OF AGENCY	Relationship to Persons Who are Handicapped		
	PRIME	SECONDARY	SAME AS OTHERS
DOT-OFAA			
Air Carriage of the Handicapped	X		
Fed. Highway Ad.-Tech. Sharing Program			X
Off. of Driver & Pedestrian			X
Highway Safety Act of 1973			X (3 exceptions)
Urban Mass Transit Adm.		X	
Dept. of State			
Off. of Medical Services			X

COMMUNITY AND RESIDENTIAL BASED HOUSING

Awareness Paper Edited By

Lex Frieden
Texas Institute for Rehabilitation and Research
Houston, Texas
Major Contributions By
Judy Heumann, Eric Dibner, and John McLaughlin
Center for Independent Living
Berkeley, California
and
Irvin Rutman
Horizon House Institute for Research and Development
Philadelphia, Pennsylvania

PREFACE

In this paper we will attempt to outline current trends in housing handicapped individuals with primary emphasis on programs in the United States. We will be discussing the needs that persons with physical and mental disabilities have in attempting to secure usable housing. By this, we mean not only the availability of accessible physical structures and ancillary services which ultimately enable the person with special needs to live as independently as possible. But, more important is the belief that all persons with disabilities must be able to select their own lifestyles. This means that there must be a system established which can meet the needs of handicapped individuals outside the confinement of specific structures and environments.

We will review many of the existing laws pertaining to housing and will provide information to show that the needs of disabled individuals have not been planned for in a comprehensive manner. We believe that this lack of planning, resulting in programs being scattered from agency to agency in a patchwork design, has meant that the majority of persons in need of usable housing have not been able to obtain it. In addition, we will try to demonstrate that, although millions of dollars have been spent on programs designed to meet housing needs of handicapped individuals, sufficient resources have not been directed to those programs. Finally, we contend that many of the funded programs are inappropriate, as they continue to segregate persons with special needs.

The White House Conference on Handicapped Individuals wishes to thank the following council members for their extensive assistance: Paul Hoffman, Jesse Brown, Albert Pimentel, Burt Risley, and Jayne Shover. Significant contributions to this paper were made by: Carroll Kowal, Rita McGaughey, Marie Thompson, and Suzanne Turner. Special thanks go to members of the Technical Review Team: Marcia Burgdorf, Developmental Disabilities Law Project, University of Maryland; Eunice Fiorito, New York City Mayor's Office for the Handicapped; James Folsom, I.C.D. Rehabilitation and Research Center; and Essie Morgan, Spinal Cord Injury Service, Veterans Administration.

TABLE OF CONTENTS

	Page
Introduction	321
Historical Perspective	321
State of the Art	323
Support Services	326
Housing Alternatives	327
Conclusions	329
Bibliography	332
Appendices	333

INTRODUCTION

The provision of shelter (i.e. housing) has been a concern of human beings since people first came in out of the rain. The rise of domestic civilization and cities has led to basic problems of environmental design. It is only in this century that attention has been concentrated on solutions to urban crowding, decay, and ghettoization. However, "different" people have continued to be relegated, along with the poor, to institutions and ghettos. This paper will outline the development of separate housing and show that programs have not yet met the needs of individuals with disabilities.

Historically, the norms society has established have resulted in persons with disabilities being considered different, special, or unmentionable by the "normals." These attitudes have led to the placement of many human beings in unnatural and repressive environments as well as to the dehumanization of disabled persons as if they were objects. In some cases the idea that a disabled individual brought luck (hunchback) or had magical powers (epileptic) led to an elevated image, but no better living situation. Improved housing was only available to those privileged with enough money to provide for all the needs of a comfortable existence. Without opportunity of self help and control over their lives, people with disabilities usually found no solutions provided for their housing problems.

Prior to modern science and sociology, persons who lived with paralysis, retardation, mental illness, deformity, or disease found help from those who loved them, or they struggled on their own. Their needs had to be met in their immediate community of friends or through tremendous personal will to survive. Often the attitudes of society precluded any but peripheral participation in mainstream activities. Ghettos of societal outcasts were created as an excuse for dealing with special housing (or socioenvironmental) needs.

In spite of the fact that many more people today survive and overcome great physical mishaps and mental trauma than ever before, archaic attitudes still prevail over their lives and environment. "The person with a handicap is frequently perceived as a deviant, and expected to play a stereotyped role." This negative value, or stigma, is perpetuated through the removal of the person from "normal" society and isolation from others' experience.[1] As a result, many persons with disabilities are separated and placed in large facilities such as housing projects, or isolated with their families rather than integrated within society.

HISTORICAL PERSPECTIVE

Prior to the development of the traditional institutional model, "deviants" were long grouped together regardless of the nature of their disability. The insane, blind, epileptic, and retarded were not separated in many people's minds from beggars, paupers, and criminals. In fact, deviants of all sorts were frequently locked up together. The Puritan ethic related one cause as responsible for all these effects.[2] Perhaps the prison and poor house were precursors of later institutional models. Largely, though, public attitude formed the prison walls that often barred the "crippled" from employment, made the deaf "dumb" in class, and ridiculed persons who were retarded. Daily life was made unaccommodating and no solutions to the problems of handicapped persons were offered outside the family.

The first American institutions were located centrally in the community and segregated, with the hope of training and returning the "deviant" to a "normal" lifestyle.

> The goal was a combination of diminishing the intellectual impairment and increasing the adaptive and compensatory skills of pupils so that they would be able to function at least minimally in society.[3]

Around 1850, positive attempts were made in developmental rehabilitation models, which resulted in a rehabilitation rate of about ten to forty percent.[4] However, many residents had no place to return to, and some people expected complete and rapid "cures" which did not occur. The nature of institutions became custodial, with permanent care necessary to shelter inmates from society. During the 1880's and later, the trend was to economize, isolate, and enlarge facilities. The prevailing sentiment was one of benevolence, though eventually work was emphasized "to provide healthful and attractive occupation."[5] The retarded and the mentally ill especially were moved to the periphery, out of sight out of mind, and "funny farms" were established.

The concept of pity behind the growth of large institutions turned to resentment that "sufferers" did not get well. "Defectives" began to be

indicted as social ills from which society must be protected. By the turn of the century, the trend was toward no education, assignment of hereditary causes, and fears that "feeblemindedness" was a factor in vagrancy and venereal disease, not to say crime and other "social evils". There were accusations that "imbeciles" bred dangerously. These indictments were voiced by presidents of the American Association on Mental Deficiency.[6] To end the propagation of the "disease" of retardation, drastic measures were attempted.

The inability of the public to view persons with disabilities as human beings led to these individuals being seen as animals. This denigration led to brutalization and sterilization. From 1895 preventive marriage laws were passed, some of which are still with us. When legislation was ineffective, compulsory sterilization became the rule. It, too, was less effective than hoped, not preventing as many cases as the hereditary theory expected, not being applicable to a wide enough population, and meeting with some moral objections. Further attempts at prevention were made through segregation, which meant to control mating and procreation by quarantine. Whereas discharges from institutions had originally been easy, alarmism created mandatory rules for permanent commitment.

To house the entire disabled population in institutions required either more money or smaller per capita cost, and funds were not forthcoming. Economic arguments were given for warehousing the disabled in as large populations as manageable. The higher-functioning residents were put to work in the fields, and arguers that institutions could become self-supporting assigned an acre per person as requisite size. Reduction of cost entailed strenuous work conditions making some institutions as much as fifty percent self-supporting. In the late 1920's per capita costs in publicly supported U.S. institutions dropped to $526 per year. Extra design features were done away with; heat and proper light were sometimes considered too expensive! Larger and larger population size was rationalized, with proposed enlargements growing from under 1000 to over 3000.

Few voices suggested reversing segregation. Education was looked on as worthless in institutions as was special education in the community, unless it could be used to identify "defectives" for permanent segregation. Monetary support to needy families in the community, offering the alternative of living outside the institution, was seen as regressive, as was the eugenic approach of new psychological clinics.

After 1920, it became clear that sterilization and segregation were not solutions. Commitment laws and confinement for life were unpopular with the families of the "feeble-minded." It was also found that "morons" were not habitual criminals nor were they misbehavers.[7] Still the relative insignificance of heredity as the cause of retardation was not known. For a while, registration was proposed with hopes of community supervision. Identification and social control did not occur. The innovations tried in the period of indictment exhausted the large institution as a rational design. However, due to a lack of community commitment and services, institutions did not change. The momentum of indoctrinated attitudes and immutability of structures, along with the Depression and World War II, perpetuated the institutional model.

Occassionally, small residential facilities with appropriate support services were established. Sometimes affiliated with churches or privately run, these projects were successful where individual consideration and tender loving care predominated. Also, certain projects were developed from time to time to house groups with specific disabilities, such as the blind or tubercular. These special solutions were limited in scope by their dependence on private funds and by serving segregated groups. Although low budgets may have been managed in some of these models, support services are known not to have been very widespread, and there was no proliferation of efforts at comprehensive programs.

Despite movements for increased personal rights and equal protection for many minorities; and despite an awakening awareness by the public about the realities of disability and the dehumanizing effects of institutions; repressive management, prejudicial practices, and substandard facilities continue to exist in and function as institutions.

Since "behavior tends to be profoundly affected by the role expectations placed upon a person,"[8] and since many people believe that disability is sickness,[9] it is no surprise that institutions have usually proven unhealthy. In a study of long term residential facilities, nursing homes were described as "little more than small, privately owned hospitals . . . not for the healthy."[10] Two well known disincentives are treating people as objects and massing "deviants" together. An institution treats people as objects by shuffling

individuals around, making them stay put, treating them as patients and not as individual human beings. By grouping many disability-types with little regard for different classes of needs and functional abilities, the rehabilitable get depressed and special needs get glossed over.

Further, inhumanity is fostered when treatment of "patients" is an opportunity to experiment, use shock treatments, and chemotherapy. In the growth of institutions, the concentration of skilled expert staff never materialized, one of the main reasons being the partially self-elected isolation of institutions remote from centers of learning and population . . . Institutions have tended to . . . retain professionals who are deviant themselves . . . The unlicensed physician, often unable to communicate in English, is notorious, as are professionals who are alcoholic, drug addicted, or unstable. Professionals not good enough to work on us or our normal children were, it seems, good enough to work on someone else's (disabled) children. Employers as much as residents, become "institutionalized."[11]

Finally, the institutional model requires people to move from their homes and families. The reality of the situation is that moving for most individuals is difficult. One leaves friends, relatives, and familiar surroundings. When this choice has been made freely, the trauma is not as great. However, when the move is merely made in order to secure some facsimile of adequate housing and services, these problems become more severe. It is not uncommon to hear persons who are elderly or disabled complain that one of the biggest problems in moving to an institution is that they lose their will to live.

STATE OF THE ART

Advances in medical science and health technology in the last thirty years have "increased the survival rate of victims of accidents, disease and disability to a near-normal life expectancy and has greatly extended the lifespan of the elderly and the infirm"[12] offering the opportunity, but not the resources to return as productive members of society. Handicapped persons can maintain their health with certain provisions, but that may be no consolation if they do not have access to appropriate housing, jobs or transportation. If the environment is inaccessible, life, though antiseptic, may be cruelly isolating. Modern theory of housing design for disabled individuals has realized the importance of choice and provision of pathways for normalization.

The concept of normalization entails processes to bring anyone handicapped to his/her optimum potential functional level. This will not be accomplished with just edifices or several projects. It requires a systematic approach.

There has always been a portion of the disabled population who have lived independently. The lack of widespread acceptance of such a lifestyle is due, in part, to the service-void at the community level. Those disabled persons who can manage apartments or rooms, or consider boarding or convalescent settings sufficiently independent, have been restricted in their choices and activities, and often relegated to a small niche. Not only has the environment discouraged mobility, but fears of fire hazards, insurance costs, or the ability for self-care by a disabled person add further disincentives. Restrictions like one hundred per cent segregated living (Sec. 202), no attendant care allowance (in most states), cost and size guidelines (F.H.A.), Section 8 counted as income (Social Security), and self-support plan limits (Departments of Rehabilitation) prevent individuals from obtaining their maximum possible functional independence in the living arrangement of their choice.

One of the biggest difficulties in providing usable housing is the lack of coordinated legislation and the lack of thorough implementation of those guidelines which are in existence. There are many programs and laws in the United States today designed to assist and protect handicapped individuals (see Appendices A & B). However, due to the fact that legislation has not been implemented to provide comprehensive planning and delivery of services, these programs and laws are often ineffective.

For example, the Architectural and Transportation Barriers Compliance Board was established by Congress through the Rehabilitation Act of 1973. Currently, the Board is only involved with insuring that P.L. 90–480, the Architectural Barriers law, is complied with. This task is proving most difficult because of the apparent inability of the government agencies to enforce existing regulations.

Exclusion of the Post Office from compliance and the lack of power of enforcement weaken the Compliance Board. As a monitoring and planning mechanism, it must be strengthened. The law "should contain all necessary mandates with respect to enforcement, including penalties for

non-compliance and/or benefits (for) prompt adherence to a law which might provide for gradual compliance."[13] Other obvious difficulties with the effectiveness of the Board stem from the fact that it is composed of individual department heads who are charged with monitoring themselves.

Even if this Compliance Board were effectively monitoring construction of federally financed housing and other federally funded programs, there is still no program which has been designed to ensure that needs such as attendants, and curb cuts are incorporated into communities so that disabled individuals could live independently; and, although all states have some legislation which requires that when State funds are being used for construction, buildings should be barrier free, there is no real enforcement mechanism to guarantee compliance in most states.

Legislative advances in the last twenty years have begun to open doors for the disabled in many countries. The noteworthy Swedish provisions[14] show how the rights of disabled people can be guaranteed. In the United States the surface has been scratched, although many deeper measures are necessary before an equal society is guaranteed. Concern for all minority groups indicates a shift in attitude, although the environment has not changed much for a disabled person needing housing or desiring to visit friends.

In order to promote integration, it is highly desirable that disabled as well as non-disabled persons pay visits to each other and have *free choice of their own living unit.*[15] "The integration of handicapped persons within the population should be an identified goal in private as well as public housing."[16]

"The principle of integration, when applied to living arrangements for the disabled, requires a major shift of primary design criteria . . ."[17] Attention should be given to the availability of fully adapted living units to wheelchair users for individual as well as congregate living.[18] Adaptable design allows that "any or all spaces and facilities can if necessary be made accessible by adding or subtracting elements."[19] Besides "a door handle requiring downward pressure instead of a twisting motion" and "all approaches level,"[20] "provision of personal space and protection of territoriality of the occupant of that space," is important. Also, "cues as to ones orientation, achievable by design of environments which are differentiated from other proximate spaces by size, shape, form, materials, texture, color, and detail" are fundamental for the "retarded, cerebral palsied, epileptic, and confused elderly."[21]

There has been lots of recent literature and ergonomic research documenting the parameters of design for the disabled. *Barrier Free Site Design* from H.U.D. and American Society of Landscape Architects shows what can be done outdoors, and more and more books like this are refining the specifics of accessibility so that most professionals have begun to understand.

Standards for Residential Facilities for the Mentally Retarded adopted in 1971, the A.N.S.I. Standard 117.1 in 1961, and Public Law 90–480 in 1968 provided action in new construction in the public sector toward barrier-free design, and provided that each federal agency develop standards unique to its particular type of construction. However, this legislation has lost some of its usefulness over the years.[22] Varying interpretations of specifications and applicability, the lack of drawings (such as English and Swedish standards include), and non-coverage of residences are drawbacks.

Concerned communities see that "Federal legislation leaves a great many buildings outside its scope." "There has been little litigation" to demonstrate that "the right denied is extremely important and the discrimination and damge are evident."[23] "Statutes are riddled with waiver clauses,"[24] and almost no communities have protection for the disabled in housing codes. Another problem is the ambiguity of codes, from state to state and agency to agency. "The legislation should, as a minimum, establish the framework for local mechanisms to achieve the objective of barrier-free architecture, possibly in terms of performance rather than specific quantitative measurements. The law should provide for ongoing critical review of performance and necessary follow-up with respect to specific buildings."[25]

The disabled have been included in the federal concept of anti-discrimination in housing, in the Housing Act of 1964, but historically, there has been no legal recourse to violations. Some states have waiver clauses that may be invoked to exclude prospective tenants (as in the case of disallowing blind people if they have guide dogs; California Civil Code sec. 54.1). "H.U.D. handicapped accessibility standards have been interpretated to apply to only ten per cent of the elderly housing units which unduly limits the

number of living units which are made accessible."[26]

It is interesting to observe that in some cases H.U.D. limits the number of barrier free units in its projects; while in other cases, where completely accessible projects are constructed, H.U.D. requires occupancy by persons who are either elderly or handicapped. In both of these cases, free integration of handicapped and non-handicapped individuals is effectively prevented.

Sometimes, "handicapped people elect to be closely associated with one another in special programs or housing. Het Dorp is a good example."[27] "It is a 400-unit community of severely handicapped persons from throughout Holland, isolated from the city, and located on hilly ground which necessitates the use of electric wheelchairs for mobility."[28] Note, however, that in Het Dorp's complex "there isn't too much interaction among the residents," and the Dutch collective facilities "gradually become more institutional in tone" because residents "inevitably become more and more dependent."[29] The right to risk is basic to the right to participate, and handicapped persons should not be segregated under the misguided impression that precaution is needed at the expense of independence.[30] "To live independently one need not be physically independent," but "control over his own life, and the extent to which he does influence his own destiny determines the degree of independence he maintains."[31]

The role of consumer participation in rehabilitation and housing efforts is becoming more recognized as essential. "The law should contain some authorization for involvement of groups of disabled people in planning and evaluating the effectiveness of the enactment, possibly including financial help to enable such groups to plan for or judge the effects of other people's planning with regard to the real needs of disabled people."[32] Self-determination and human rights in treatment, rehabilitation and housing is a basic and inviolable tenet.

In spite of frustration caused by the lack of program coordination and ineffective implementation of regulations, noteable progress in housing disabled persons in the community is being made.[33] In Houston, Texas, for example, more than eighty severely physically disabled persons are clustered in four separate apartment complexes located in different parts of the city.[34] These individuals share support services as well as responsibility for managing those services. Other communities have, to a limited degree, replicated these efforts to provide suitable alternatives to nursing homes and over-protective families.

Perhaps less institutional than the systematic approach of providing support services in the context of a specific physical structure is the concept of making support services available to an entire community. The Berkeley, California model is unique in this respect as the Center for Independent Living (C.I.L.) is not a live-in program. It is an office which is staffed with a significant number of persons who themselves are disabled. These individuals manage, among other things, a community-wide transportation service, peer advocacy and counseling service, and attendant referral service.

Experience in these programs indicates that many handicapped persons, particularly those who have adapted to a protective living arrangement or who have been segregated from the general population, may require some sort of life adaptive skills training to facilitate their adjustment to a more independent living arrangement or their integration back into the community. Such a program has proven helpful to blind persons in Richmond, California where mobility training and counseling are being provided in the context of a normal apartment complex. In this program, participants are able to practice independence and develop self confidence.

These housing or living experiments have only been functional for the last three or four years and there is a great deal of development and research into alternative models which must occur before any unqualified judgements can be made about the quality of life stimulated by these environments. It appears as if these arrangements can be cost-effective and considerably more satisfactory from an individual viewpoint than those heretofore available alternatives.[35] Also, it appears as if there is a need to provide a spectrum of alternative living arrangements so that individuals may choose that which suits them best.

The federal government has recently made a number of potentially positive steps to encourage independent living by handicapped individuals. For example, the 1974 Housing and Community Development Act includes provisions for rent subsidies to be paid to qualified handicapped individuals who may choose their own dwellings (see Appendix A). The Rehabilitation Services Administration continues to fund the sort of research and demonstration project which led to the developments in Houston and Berkeley. The

Veterans Administration is assisting mobility impaired veterans to be more functionally independent by providing them grants to make their homes adaptable and barrier free.

SUPPORT SERVICES

Obviously, removing architectural barriers will assist many disabled individuals. However many unique services are needed by handicapped individuals according to their disability, and for these persons to lead a normalized life, these services should be available in their immediate community or home environment. Dependency resulting from disability may have many profound consequences. Society requires many persons with disabilities to depend on the charity of other people. This results in needless conflicts. For example, a person with a disability who is in need of assistance to get in and out of bed must use the *services* of another individual. When the disabled individual is unable to pay for this *service,* he/she is dependent on the helpful individual. This type of a relationship often fails to enable the disabled individual to get up at the most appropriate time. Rather, the disabled person must structure life around time available for the "helpful" individual. Additionally, the disabled individual may not be able to choose an aide who will best meet his/her physical needs, as well as his/her personality needs.

In California, a person who is in need of more than twenty hours of attendant care per week is defined by the State as being severely disabled. This individual is eligible to receive a maximum of $505 from the Social Service department for attendant care. Additionally, this individual is eligible to receive $295 a month from Supplemental Security Income (SSI). Attendant care monies come from Title XX which is a State-Federal matching program. The State also supplements SSI.

In most other states there are no programs which provide a disabled individual with attendant care monies. According to the U.S. Census of 1970, 52% of those persons defined as being disabled have incomes below $5200 per year. One may conclude that most persons in need of such assistance are unable to pay for this service. Thus, dependency is created.

Attendants are needed to assist handicapped individuals with many sorts of special needs. Some programs refer to attendants as parents. Again, this role means that the parent is in charge. With disabled adults, irrespective of the disability, the optimum goal is as much independence as possible. Thus, the approach used to provide assistance should ensure that the disabled individual will have the opportunity to be in charge of the situation.

A number of effective attendant arrangements have been demonstrated. At the Center for Independent Living in Berkeley an attendant care counselor interviews individuals interested in this kind of *work.* The disabled individual who is looking for a *worker hires and fires and directly pays* the individual for *services* rendered. There is also an emergency attendant program which was created to assist an individual when the regular attendant is not available or some other problem occurs. There is an extensive outreach program in the community which makes persons aware of the services being provided by the Center.

Shared attendant services may be very efficient and cost-effective.[36] Living arrangements involving small groups of four to eight are fairly easy to manage. With larger groups, attendant staffing and scheduling becomes complicated and administrative tasks multiply. Everyone in the group should assume a share of these responsibilities, whether they do so by hiring someone to manage the system or by dividing the work among themselves.

In order for a mobility impaired individual to freely get around in the community, transportation is essential. Current public transportation systems do not meet the needs of people who are unable to ambulate steps. Such a system produces undo hardship on this class of individual. Private transportation systems often charge exorbitant amounts of money. Such cost means that the disabled individual is unable to travel in the community as other people who are able to use public transit do. Legislation should be passed which will ensure that all vehicles purchased in the future will be accessible to *all* individuals. The Federal-Aid Highways Act of 1974 amended its definition of handicapped to include persons in wheelchairs. However, the definition of handicapped in the Urban Mass Transportation Act of 1970 does not specifically include persons in wheelchairs. S.662, which passed the Senate in September of 1975, would amend existing laws to include the provision. Even if legislation is passed which guarantees that all new transportation systems be designed to meet the needs of all persons in our society, there will not exist a

system to meet the current transportation needs of more severely disabled individuals for many years.

Routine medical checkups, occasional treatment, specialized equipment and supplies are needed by persons with disabilities to facilitate and maintain their mental and physical health. Health services, wheelchairs, prostheses, hearing aids, tape recorders, and so forth, are very expensive. It has been suggested that the government assume the responsibility for providing the services and hardware which handicapped persons need as a result of their disability. One major problem disabled people have is in obtaining health insurance which will meet all their medical needs. One of the major disincentives for disabled persons who are served by Medicaid or Medical is that when their income goes too high they will lose this benefit. There is a need to provide comprehensive health insurance which will meet all the medical needs of disabled people. Until such a program is instituted many disabled individuals who could work will be unable to do so.

HOUSING ALTERNATIVES

The following section of this paper is taken from a position paper prepared by Irvin Rutman on behalf of the National Institute of Mental Health for the White House Conference on Handicapped Individuals. This section provides an excellent basis for definition and discussion of various sorts of alternative living arrangements. (References for this section may be found on page .)

"Although a variety of models and approaches regarding residential alternatives have been developed, agreed-upon classifications do not exist. To establish a point of departure, we may consider the following as a generic definition of a residential care facility:

> A community-based housing facility used as an alternative to hospitalization or institutionalization that provides 24-hour non-medical care to a number of individuals for a designated length of time in a structured, supportive environment. The facility may or may not directly provide additional rehabilitative programs, but the major goal for the client is his active participation in community life to the fullest degree that he is able.[17]

The following types of programs are generally included within the continuum of residential care facilities:

Foster Homes—family settings in which relatively small numbers (typically, 1–6) of individuals, children or adult, live in a private home with a sponsoring family in a setting characterized by a family-like environment. Includes both individual and group foster homes.

Boarding Homes (also board and care facilities)—residential facilities providing room and board to groups of from 3 or 4 to as high as 15–20 individuals. Typically are operated by untrained proprietors and provide few services other than provision of room, board and minimal supervision.

Halfway Houses—community-based residential settings providing transitional living experiences to groups of from about 6–25 clients, with the average number about 16. Predominantly nonprofit in nature, they typically offer a variety of personal adjustment, counseling and socialization experiences in addition to basic room and board services. Most halfway houses are "free-standing organizations," some, however, are affiliated with other organizations such as rehabilitation centers, hospitals, mental health associations, community mental health centers, etc. Most, although not all, are established as transitional and operate under a maximum time limit which ranges from 3–12 months.

Apartment Programs (also sheltered apartments, cooperative apartments)—Residential units designed to accommodate 2–4 persons in apartment settings. Typically designed for individuals capable of higher levels of independent functioning so that live-in staff are not required. Often affiliated with a parent corporation such as a rehabilitation center, community mental health center, hospital, church organization, etc.

Specialized Transitional Facilities (quarter-way houses, three-quarter-way houses) residential facilities designed to provide a transitional experience between an institution and another protected environment, or between another protected environment (i.e., halfway house) and the community. Quarter-way houses tend to be located in or near the grounds of the institution; three-quarter-way houses are usually located in normal neighborhood locales.

Long-term Care Facility (also long-term community home, personal care home)—community-based housing for individuals who require long-term or permanently supervised living situations

and who may need minimal nursing-type care. Such individuals are usually physically mobile, able to accomplish some of their self-care needs with some supervision, but otherwise tend to lack the resources to cope with the problems of daily living and will seldom be able to live independently in the community.

More specialized in nature than the types outlined above, but deserving of mention, are the following additional programs:

Nursing Homes: Facilities for acutely or chronically ill persons who require attention by medically trained staff, including nurses. Services might include executing treatment plans and administering medications as ordered. Skilled nursing homes serve persons not in need of hospital care but requiring skilled nursing care. Such individuals may be bed-fast or ambulatory, but so handicapped that they are unable to care for themselves. Intermediate nursing care facilities serve persons not needing hospital or skilled nursing care but still requiring limited nursing care. Such persons are semi-ambulatory and have some self-care skills and may be capable of becoming involved, under supervision, in some community activites.

Lodges—a specialized residential-vocational model utilized primarily for the mentally disabled in which formerly hospitalized patients are helped to secure, furnish, and operate a communal residence with minimal or no staff involvement. In addition, lodges typically establish small semi-skilled business ventures to enable the lodge members to become employed and self-sufficient. Lodge-type programs exist in some 15–20 states throughout the nation.[13]

Domiciliary Care programs—programs authorized as part of the Supplemental Security Income (SSI) legislation were intended to facilitate residential care for disabled and aged individuals. Special supplementary funding incentives are designed to facilitate the creation of domiciliary care settings which, in general form are similar to boarding home programs as described above. SSI guidelines, however, require special case management, monitoring and training procedures to assure the provision of adequate domiciliary care services, as well as some minimally prescribed personal supervisory care by the domiciliary care proprietor.

Classifications

In considering this array of community residential alternatives, it is helpful to organize them according to certain key variables. Although numerous organizational frameworks are possible, we shall limit ourselves to the following two:

It will be noted in the preceding table, as well as the one that follows, that some overlap exists between categories.

A second type of classification is in terms of capacity for independent functioning. Along this dimension, the array of facilities would be distributed as follows:

Cost of Housing Alternatives

As might be expected, cost factors in this field (1) vary widely, and (2) are difficult to ascertain. Several variables tend to correlate with costs: the auspice of the residential program; whether it is non-profit or for-profit; the extent to which additional program services (i.e., counseling, therapy, recreation, vocational preparation, follow-up, etc.) are provided by the facility; the size and qualifications of the facility staff; and the condition and location of the physical plant and furnishings.

It is impossible, in the space allowed, to discuss all of these factors in detail. However, some general trends and dimensions regarding costs may be briefly noted. First, it is almost axiomatic that the more extensive and enriched the total program offering is, the more expensive the residential costs will be; therefore, facilities which provide counseling, re-socialization, therapy, medical follow-up, vocational training and the like, as part of the total program, will show higher operating costs. Next, there is a tendency for free-standing facilities to be less costly than those associated or affiliated with parent organizations. This may be the result of duplication of certain administrative overhead and/or personnel costs.

Auspices of the facility will also tend to influence costs. The findings of a national survey of halfway houses, completed in 1975[12], show that municipal or state-operated facilities tended to have the lowest average number of clients per facility, followed by private, non-profit facilities, then federally-auspiced facilities, then finally, profit-making facilities. Moreover, when per diem costs were examined, it was found that the for-profit facilities reported higher per diem costs

($18.30) than either federal ($12.30), state ($14.70), or private non-profit programs ($13.80). According to this survey of halfway house type programs, it can be generalized that large private, profit-making facilities are characterized by a large number of clients, high per diem costs, a large full-time staff, and relatively few professional staff. Public (i.e., federal, state) facilities have a higher proportion of professionals on their staff and report lower per diem costs.[12]

According to national statistics, per diem costs for halfway houses currently fall within the general range of $12 to $18 per day, with the average at approximately $16.[6],[12]

Boarding homes and long-term care facilities (which generally offer fewer services) operate at a noticeably lower cost rate: a fair estimate would be that the per diem costs in such facilities would fall within the range of $7 to $15.

Apartment programs are still less expensive to operate because of lower plant and staff costs and fewer on-site services are required. Per diem costs for supervised apartment living may be estimated to fall within the range of $3 to $8 per client—although this is by no means a well-documented figure. Supervisory costs, as distinct from the apartment rental, for providing these services may be as low as $1 to $2 per diem.[4] At the other extreme, skilled and intermediate level nursing homes require the highest per diem expenditures; a reasonable estimate of per diem costs for such facilities would be between $20 to $30 or even higher."*[37]

It should be noted that cost of living arrangements may be both material and nonmaterial, while benefits are mostly non-material. Material costs may be relatively low for those persons who live in multi-resident dwellings and share life support services. On the other hand, material costs may be relatively high for those persons who choose to live alone and hire a full time personal attendant, or those who live in more institutionalized settings.

Non-material cost includes frustration caused by waiting and compromising, insecurity caused by undependable attendant services, or uncertainty about arrangements, and boredom resulting from routinization and segregation. Some non-material costs, like frustration and boredom, may be higher in more institutionalized settings, while other non-material costs, like insecurity, may be higher in less institutionalized arrangements.

The Swedish approach to housing for handicapped individuals suggests that a reorganization of priorities is needed in planning alternate living arrangements for institutional living. The Fokus model, in Sweden, arranges accessible housing at two-thirds the cost of living in a nursing home, including rent and service, charging about twenty per cent of the resident's income. "Urban and rural districts have communally employed home helpers who serve old, sick, and disabled people."[38] Fokus enables handicapped people to live securely under the same conditions and with the same opportunities as non-handicapped, in a chosen geographical area, with access to reliable personal service, transportation, work, and satisfying free-time activities.[39]

CONCLUSIONS

One must look at housing from a holistic perspective to recognize the need for a comprehensive approach. Because every individual has different needs, there must be a number of living arrangements available to choose from. Community support services and various solutions to special problems are needed to supplement school and work, recreation and family. Clusters of homes may be the largest facility

practicable for satisfying the complex of human housing needs.

Few people realize the extent of the problems which face every handicapped individual who is in need of housing in the United States today. When solutions are brought forth it is often believed that cost is excessive. Furthermore, there is a definite lack of *coordination* of effort, and there is a need to improve the *methods of implementation.*

Some of the problems result from a demographic void: "There is a lack of statistical data of those handicapped persons in particular who are affected."[40] No one knows how many people are in what kind of housing and at what advantages or disadvantages. Despite some functional breakdowns appearing in *Barrier Free Site Design* by H.U.D., there is no analysis of the interface between disability and housing, per se.

Other problems become evident when one reviews the following suggestions for legislative action which have been offered by a number of sources:

1. Give outright cash grants to disabled individuals to enable them to modify their own homes.
2. Pass comprehensive health insurance which will meet all the medical needs of all people.
3. Enforce existing legislation both at the federal and state levels pertaining to architectural barriers.
4. Remove all existing waiver provisions in federal and state legislation pertaining to architectural barriers.
5. Provide federal, state, and municipal monies to help create community based programs run by disabled individuals to train professionals who provide services to disabled individuals, and to develop service programs to meet the existing service needs of disabled individuals.
6. Develop and make available a compilation of *all* legislation and regulations pertaining to the needs of individuals with disabilities.
7. Educate disabled individuals on how to live independently.
8. Amend existing transportation legislation to ensure that disabled individuals will be able to use public transportation systems.
9. Adopt legislation to prohibit the development of segregated housing.
10. Do away with all work disincentives by giving grants to disabled individuals to meet extraordinary needs like attendant care.
11. As a short range goal, give disabled individuals cash grants to use toward their transportation needs. This money should not be restricted for work, medical or educational needs.
12. Ensure compliance with legislation that mandates all children with disabilities to freely receive appropriate public school educations.
13. Adopt the A.N.S.I. Standards as a minimum for the states as well as all federal administrations.
14. Encourage the development of state statutes which prevent discrimination against small living units for the handicapped through restrictive zoning provisions.
15. Establish funding sources which can provide seed monies for the development of more normal residential facilities.
16. Create residential standards which are sufficiently flexible to allow for program innovations without sacrificing the quality of care.
17. Design a cooperative market survey to analyze housing needs for the full range of handicapped individuals in terms of quantity and quality of housing and locational factors.
18. Stimulate states to make their local housing codes compatible to federal requirements.

Some of the most important changes in our society since the commencement of the atomic age have centered around the increased importance of human life as considered not just by individuals but nations, too. Humankind must find ways to adjust its governmental mechanisms to serve all individuals. The principle of affirmative action is indication that equal rights have not been provided and offers reconciliation. Breakdowns of economies and failures of rehabilitation bureaucracies are evidence of the need for new structures.

Much lip service is paid to the need of developing different housing models so that individuals with special needs would be able to select the life style most appropriate for them. Yet, when reviewing the expenditure of federal monies for model housing it is quite apparent that the traditional model of segregated housing still prevails. Many persons capable of independent living are forced to remain in rehabilitation centers, hospitals, or extended care units because community supports and accommodations suitable to their needs are unavailable. These people have never had the opportunity to live in an integrated community, with the freedom to work and travel where and with whomever they choose.

There is clearly a need to have transitional programs which will enable an individual who is moving from an institution into the community the opportunity to learn how to live in a new surrounding. But, the ultimate goal should be to create programs which will enable the person with a disability to live integrated in the community.

The role of the community in effecting or blocking integrated programs for persons with disabilities should not be forgotten. There appears to be a failure on the part of some community organizations to work aggressively with handicapped individuals. Many programs never get off the ground because of resistance from non-disabled individuals, who have grown up in a society which has basically feared or not understood the needs of persons with disabilities. It is of paramount importance to recognize this problem and to enact awareness programs in order to ensure a greater understanding from the average person.

It may seem ironic to close this paper by quoting from the *Introduction* to a list of pertinent issues which Rita McGaughey suggested for the White House Conference on Handicapped Individuals. On the other hand, it may be very appropriate to end this paper by suggesting a new commitment to solving the problems and meeting the housing needs of handicapped individuals.

> "The life styles, including the choice of housing, of all people in our country are closely related to their rights for freedom and pursuit of happiness. They are also closely related to our country's economic stability and social welfare. In considering the housing needs of persons with handicaps, it is evident that there is a need for a reorganization of national priorities based upon full recognition of the human dignity deserved by the handicapped individual just as much as the non-disabled for a realization of his self-worth. The same opportunity to select a residence of his choice should be made available to the handicapped person as it is to the non-handicapped."[41]

According to the Housing and Community Development Act of 1974 (P. L. 93–383 Sec. 101. (d) (3)), "The National housing goal" shall be to provide "a decent home and a suitable living environment for every American family." In order to achieve this goal, it will be necessary to provide adequate residential and community programs for persons with disabilities.

REFERENCES

1. Wolfensberger, Wolf. *The Origin and Nature of our Institutional Models,* Human Policy Press, Syracuse, 1975, pp. 2, 3.
2. Johnson, A., "Report of Committee on Colonies for Segregation of Defectives," *Proceedings of National Conference of Charities and Correction,* 1903, p. 246.
3. Wolfensberger, p. 24.
4. Wolfensberger, p. 27.
5. Wolfensberger, p. 31.
6. Wolfensberger, p. 36.
7. Wolfensberger, p. 54.
8. Wolfensberger, p. 2.
9. Wolfensberger, pp. 4–12.
10. Fenton, Joseph, Ed.D., *Residential Needs of Severely Physically Handicapped Non-Retarded Children and Young Adults in New York State,* Institute of Rehabilitation Medicine, May, 1972, p. 7.
11. Wolfensberger, p. 61.
12. United Nations Expert Group Meeting on Barrier-Free Design, *Barrier Free Design,* Rehabilitation International, June, 1975, p. 6.
13. *Barrier Free Design,* p. 29.
14. National Swedish Institute for Building Research, *Accessible Towns-Workable Homes* Document D9: 1972, Stockholm, 1972, pp. 4, 5.
15. The American Society of Landscape Architects Foundation, *Barrier-Free Site Design,* H.U.D. Control No. H–2002–R, 1975, pp. 18, 19.
16. Kliment, Stephen A., *Into the Mainstream,* A Syllabus for a Barrier Free Environment, RSA, HEW, AIA, June, 1975, p. 5.
17. *Barrier Free Design,* pp. 17, 19, 20.
18. *Barrier-Free Site Design,* pp. 18, 19.
19. Kliment, Stephen A., *op.cit.,* p. 14.
20. *Ibid.,* pp. 6, 9, 12, 15, 24.
21. United Nations Expert Group Meeting on Barrier-Free Design, *op.cit.,* p. 20.
22. Kliment, p. 5.
23. Kliment, pp. 6, 9, 12, 15, 24.
24. Kliment, p. 5.
25. *Barrier Free Design,* p. 29.
26. The Comptroller General of the United States, *Report to the Congress,* Further Action Needed to Make All Public Buildings Acces-

sible to the Physically Handicapped, July, 1975, p. 3.
27. United Nations Expert Group Meeting on Barrier-Free Design, *op.cit.*, pp. 22, 30.
28. Leonard, Edmond J., "Disabled Housing in Scandinavia and Holland", in *Performance,* Nov. 1975, pp. 23, 24.
29. Leonard, p. 25.
30. *Barrier Free Design,* pp. 22, 30.
31. Frieden, Lex, *Independent Living Arrangements for Severely Physically Disabled Persons,* Texas Institute for Rehabilitation and Research, September, 1975, pp. 2, 16.
32. *Barrier Free Design,* p. 29.
33. Laurie, G., Laurie, J. & McGwinn, D., Housing and Home Services for the Disabled, Elderly, and Mentally Retarded, New York: Harper and Row, in press.
34. Frieden, Lex, pp. 16–20.
35. Stock, D. & Cole, J., Adaptive Housing for the Severely Physically Handicapped, in *Rehabilitation Counseling Bulletin,* June, 1975, pp. 224–231.
37. Rutman, Irvin D., *Adequate Residential and Community-Based Programs for the Mentally Disabled,* Horizon House Institute for Research and Development, Feb. 1976, pp. 17–22.
38. *Barrier Free Design,* pp. 17, 19, 20.
39. Leonard, Edmond J., p. 9.
40. *Barrier Free Design,* p. 7.
41. McGaughey, Rita, position paper on "Adequate Residential and Community Programs for Persons with Disabilities," National Easter Seal Society for Crippled Children and Adults, March, 1976, p. 1.

BIBLIOGRAPHY

American Society of Landscape Architects Foundation, *Barrier-Free Site Design,* HUD Contr. No. H–2002–R, 1975.

Architectural and Transportation Barriers Compliance Board, *Freedom of Choice,* DHEW, October, 1975.

Comptroller General of the United States, *Report to the Congress,* Further Action Needed to Make All Public Buildings Accessible to the Physically Handicapped, July 15, 1975.

Fenton, Joseph, Ed. D., *Residential Needs of Severely Physically Handicapped Non-Retarded Children and Young Adults in New York State,* Institute of Rehabilitation Medicine, May, 1972.

Frieden, Lex, *Independent Living Arrangements for Severely Physically Disabled Persons,* Texas Institute for Rehabilitation and Research, September, 1975.

Kliment, Stephen A., *Into the Mainstream,* A Syllabus for a Barrier Free Environment, RSA, HEW, AIA, June, 1975.

Laurie, G., Laurie, J. & McGwinn, D. *Housing and Home Services for the Disabled, Elderly, and Mentally Retarded.* New York: Harper and Row, in press.

Leonard, Edmond J., "Disabled Housing in Scandinavia and Holland," in *Performance,* Nov., 1975, p. 25.

McGaughey, Rita, Position paper on "Adequate Residential and Community Programs for Persons with Disabilities," National Easter Seal Society for Crippled Children and Adults, March, 1976.

National Swedish Institute for Building Research, *Accessible Towns-Workable Homes,* Document D9: 1972, Stockholm, 1972.

Rutman, Irvin D., *Adequate Residential and Community-Based Programs for the Mentally Disabled,* Horizon House Institute for Research and Development, Feb., 1976.

Stock, D. & Cole, J. Adaptive housing for the severely physically handicapped, *Rehabilitation Counseling Bulletin,* June, 1975, pp. 224–231.

United Nations Expert Group Meeting on Barrier-Free Design, *Barrier Free Design,* Rehabilitation International, June, 1975.

Wolfensberger, Wolf, *The Origin and Nature of our Institutional Models,* Human Policy Press, Syracuse, 1975.

APPENDIX A
FEDERAL AGENCY HOUSING LEGISLATION*

Department of Housing and Urban Development

A. Authorization

Community Development Block Grant: Title I, Section 103 of the Housing and Community Development Act (HCDA) of 1974.

Section 231: Section 201 (a) of the Housing Act of 1959

Section 8: Title II, Section 8 of the HCDA of 1974

Section 202: Title II, Section 7 of the HCDA of 1974

Research into housing the handicapped: Title VIII, Section 815 of the HCDA of 1974

Comprehensive planning: Title IV of the HCDA of 1974

B. Purpose

Nonprofit or profit motivated groups and public agencies may sponsor the construction or rehabilitation of specially designed rental housing for the elderly or handicapped under the Section 231 mortgage insurance program. This program provides for insured loans at 8 1/2 percent interest, plus 1/2 of one percent mortgage insurance premium. (The rate is subject to periodic redetermination.)

Section 202 construction loans are available to nonprofit and corporative sponsors of housing specially designed for the handicapped, participating in the Section 8 Housing Assistance Payments Program. Final regulations are being developed for the Section 202 program.

The new Section 8 Housing Assistance Payments Program for Lower Income Families, as authorized by the Housing and Community Development Act of 1974, assists handicapped persons who cannot afford decent housing on the private market. Projects may be financed by FHA-insured loans or other acceptable methods of financing, with Section 8 assistance being provided on behalf of eligible lower income persons and families through assistance payments contracts with the housing owners.

C. Eligibility

The statutory definition for the Section 231 and Section 202 programs, as amended by the Housing and Community Development Act of 1974, provides that a person shall be considered handicapped if such person is determined, pursuant to regulations issued by the Secretary, to have an impairment which: (1) is expected to be of long, continued duration, (2) substantially impedes his ability to live independently, and (3) is of such a nature that ability could be improved by more suitable housing conditions. A person shall also be considered handicapped if such person is a developmentally disabled individual as defined in Section 102 (5) of the Developmental Disabilities Services and Facilities Construction Amendments of 1950.

A handicapped person may receive Section 8 assistance in existing housing which is suitable for occupancy by a handicapped person. Projects may be constructed or rehabilitated to contain some specially designed units. Or, an entire facility may be designed for occupancy by the handicapped. All units may be assisted under Section 8 in the case of projects designed for the handicapped.

D. Scope

a. Community Development Block Grant Program

The regulations, guidelines, and policy governing the implementation of the Community Development Block Grant Program (CDBG) stipulate that the Architectural Barriers Act of 1968, 42 U.S.C. 4151, is applicable to any assistance given under the program. The design of any project built with such funds must comply with the *American Standard Specifications for Making Buildings and Facilities Accessible to and Usable by the Physically Handicapped* (ANSI A117.1). This includes any project work now eligible under CDBG which formerly would have been built under the categorical programs. Categorical grantsmanship was replaced by entitlement funds allocated on the basis of community size, poverty, and the prevalence of overcrowded housing, with very few strings attached.

Two titles in the Act are currently administered by the Assistant Secretary for Community Planning and Development: Title IV is the amended "701" Comprehensive Planning and Management Assistance Program; Title I is the Community Development Block Grant Program which consolidates several former categorical programs: Urban Renewal/NDP, Model Cities, Water and Sewer, Neighborhood Facilities, Public Facility Loans, Open Space Land, and Rehabilitation Loans.

*From: Architectural and Transportation Barriers Compliance Board, *Freedom of Choice*, DHEW, October, 1975.

Under Title IV, $100 million has been appropriated for fiscal year 1975 to aid comprehensive planning for urban and rural development and to assist state and local governments to establish and improve planning staffs and techniques on an area-wide basis. Eligible recipients include states for state-wide planning and assistance to sub-state applicants applying to the states; large cities, urban counties, metropolitan clearing houses, councils of government, Indian tribal bodies, and other governmental applicants with special planning needs that cannot otherwise be met.

Recipients are required to carry out an ongoing comprehensive planning process involving citizens and to develop a comprehensive plan which includes, as a minimum, a housing element and a land use element. The plan should address the needs of all citizens including the elderly and handicapped. Both elements must specify goals and measurable annual objectives, programs to accomplish the objectives, and program evaluation criteria. In addition, land use policies must be coordinated at all governmental levels and functional planning must be integrated with comprehensive planning.

Activities which may be undertaken under Title IV include natural resource planning; planning for physical land use facilities and service delivery systems including health, recreation, education, culture, transportation, utilities, fire protection, and police; economic development planning including employment; equal opportunity planning, financial planning, evaluation, and research.

The extent of citizen involvement is determined by the applicant according to the level of government and the nature of the activity under consideration. The applicant must include a statement of the extent of citizen interaction in starting as well as in responding to proposals, the extent of access to the decision-making process (i.e., involvement where major plans, policies, and priorities or objectives are being determined). But citizen involvement does not require citizen concurrence in final determinations. The latter is the sole responsibility of the applicant.

Although the program serves all Americans, nothing in the statute is geared specifically toward the handicapped, nor is the administrative focus of the program in this direction. Because 701 grants are relatively small, there is less likelihood that a recipient will be able to study the needs of any special group in depth after meeting the mandatory comprehensive planning requirements, but, at the same time, this possibility is not precluded.

Under Title I, $8.6 billion has been authorized for community development activities, including budget authority for $2.55 billion for fiscal year 1975 and a request of $2.75 billion for fiscal year 1976. States, metropolitan cities, and urban counties are eligible for the entitlement grants under the Act and states and other units of general local governments are eligible for discretionary grants. Metropolitan cities and urban counties, and in certain cases other units of general local government, are eligible for hold-harmless grants. The grants must be used to develop viable urban communities, including decent housing and a suitable living environment and expanding economic opportunities principally for persons of low and moderate income.

Certain activities are mandatory for the applicant to receive Title I entitlement grants: preparation of a housing assistance plan and a community development plan summary, program, and budget to determine needs, goals, and objectives. The plan must identify the needs of the entire population including the handicapped.

The housing assistance plan must include the housing needs of the low-income elderly and handicapped with data and planning for their housing as a distinct component. Title I funds may be used to acquire sites for housing, including housing for the handicapped. Funds may be used for rehabilitation financing, including funds for handicapped homeowners. Funds may also be used to undertake comprehensive code enforcement projects to upgrade housing, including that occupied by the handicapped.

Under Title I a broad range of public works and facilities are eligible which may benefit the handicapped as well as the general population—streets, sewers, fire protection services and facilities, parks and playgrounds, for example. Neighborhood facilities, which may house programs for the handicapped, are included. Similarly, senior centers may be funder under the new Act. A further provision is the use of Title I funds to remove material and architectural barriers restricting the mobility of the handicapped. Such barriers may be removed in existing buildings and must be removed in new construction, altered, or leased buildings. Barrier removal might include ramps, railings, or slope gradations.

Public services are eligible activities if they are in support of other community development activities. To be supportive, they must be located in an urban renewal area or concentrated code enforcement and rehabilitation area or they must apply directly to a physical development activity permitted under Title I. For example, funds could be spent for homemaking services or tenant counseling in a handicapped housing project which is being rehabilitated with block grant money.

Environmental review and relocation requirements as they apply to the new Act do not focus on specific population groups. However, "last resort housing" may be used for groups such as the handicapped if no other appropriate housing is available for them in the relocation process.

A citizen participation plan must be developed for involving citizens in preparing the application prior to submission. Handicapped citizens may suggest needs, express activity preferences, and assist in selecting priorities for the plan and program. They may also assist in program implementation by monitoring activities related to their interests and by employment in the program and involvement in its evaluation. Although final determination on the use of the funds is the sole responsibility of the recipient, the recommendations of

citizens must be taken into account. In the decision-making process, the handicapped and their advocates must compete in the area of community interest groups for a share of the money to meet their needs.

In addition to the entitlement funds, certain funds which may serve the handicapped are available at the discretion of the Secretary. While not designated specifically for them, discretionary funds allocated to new communities, for example, may be used for projects meeting their needs. As a minimum, new communities must conform to the Architectural Barriers Act if they receive block grant funds.

Discretionary funds are also available for innovative projects which encompass a concept, system, or procedure that is unique, advance the state of the community development art, and have the potential for transferability, based on priority areas of national significance established each year by HUD.

Monitoring procedures are currently being prepared by HUD. Monitoring will be limited to determining whether the recipient has met the requirements of the Act and other related statutes rather that focusing on the merits of any local program or the specific activities within it.

The impact of both the amended 701 program and the new block grant program in meeting the needs of the handicapped should become evident as both programs become operational this year.

b. Development of HUD-assisted housing for the handicapped

Nonprofit or profit-motivated groups and public agencies may sponsor the construction or rehabilitation of specially designed rental housing for the elderly or handicapped under the Section 221 mortgage housing program. This program provides for insured loans at 8 1/2 percent interest (subject to redetermination), plus 1/2 of one percent mortgage insurance premium.

Section 202 construction loans will be available to nonprofit sponsors of housing specially designed for the elderly or handicapped, participating in the Section 8 Housing Assistance Payments Program. Final regulations are being developed for the Section 202 program.

The statutory definition for Section 231 and Section 202 programs, as amended by the Housing and Community Development Act of 1974, provides that a person shall be considered handicapped if such person is determined, pursuant to regulations issued by the Secretary, to have an impairment which: (1) is expected to be of long, continued duration, (2) substantially impedes his ability to live independently, and (3) is of such a nature that such ability could be improved by more suitable housing conditions. A person shall also be considered handicapped if such person is a developmentally disabled individual as defined in Section 102(5) of the Developmental Disabilities Services and Facilities Construction Amendments of 1950.

The new Section 8 Housing Assistance Payments Program for Lower-Income Families, as authorized by the Housing and Community Development Act of 1974, offers the best vehicle for assisting handicapped persons who cannot afford decent housing on the private market. Projects may be financed by FHA-insured loans or other acceptable methods of financing, with Section 8 assistance being provided on behalf of eligible lower-income persons and families through assistance payments contracts with the housing owners.

A handicapped person may receive Section 8 assistance in existing housing which is suitable for occupancy by a handicapped person. In addition, projects may be constructed or rehabilitated which will contain some specially designed units or an entire facility may be designed for occupancy by the handicapped. All units may be assisted under Section 8 in the case of projects designed for the handicapped.

c. Housing the handicapped under the various HUD programs

Thus far HUD has helped develop eight buildings designed wholly or in part for occupancy by handicapped or disabled persons. The lessons learned from their construction and operation can contribute meaningfully to accomplishment and progress in this field.

Vistula Manor

The first public housing for handicapped people was developed in Toledo, Ohio, in 1967. The building had 164 units, half to be occupied by the handicapped, half by the elderly. When it opened, only 17 units, or 10 percent, were occupied by handicapped persons. Since then the percentage has risen about 2 percent per year, so that even today fewer than 30 percent of the occupants are handicapped.

The building borrowed from designs of Dr. Howard Rusk's Rehabilitation Institute of New York. It featured lowered mirrors, sliding doors, shallow adjustable kitchen sinks, raised electrical outlets, a single water faucet control, a lap board 27 inches from the floor, and a bathtub with a seat at one end.

For several years six units were leased to Goodwill Industries located across a highway from the building, but neither the nearby presence of Goodwill nor the use of the apartment units developed any significant administrative links between the two.

Pilgrim Tower

This building was sponsored by the Pilgrim Lutheran Church of the Deaf in Los Angeles. Opened in 1968, the 112 units were built with a Section 202 direct loan with the aim of serving primarily the deaf and hard of hearing. Seven out of every eight current residents are deaf or hard of hearing. Architecturally, the building is designed essentially for the elderly.

The sponsor developed a significant signalling system that has been studied frequently since then. A control panel in the manager's office has indicators for each apartment. The panel turns on bright 6-inch high lights in each apartment that pulse on and off to indicate that the manager is signalling. Thus sign lled, the resident turns the TV on to a closed channel and sees the manager signalling in the sign language of the deaf. In turn, residents can use the system for reverse signalling. Cost of the system was $22,000, which would have been less if installed during construction.

The large community room on the ground floor presents a graceful, fascinating spectacle, with residents signalling to each other in sign language in total silence. The degree of personal interaction is high, but the building's sound level is, of course, very low. All building personnel can use sign language.

Center Park Apartments

This Seattle, Washington, project opened in October, 1969, with 150 units, all for the handicapped. Here the architects carefully studied the lessons of Vistula Manor, adding a number of needed features. They provided elevators large enough to hold six wheelchairs; electric door plates for entrances; sink faucets at the side of the sink; adjustable sink counters; folding closet doors; higher electric outlets; emergency door pulls or wands; sliding bedroom and bathroom doors; lever door handles useful for arthritics and persons with hand, arm, and shoulder limitations; ball-bearing kitchen drawers.

This public housing project was additionally sponsored by the Seattle Handicapped Club, which ultimately helped fund a day center building adjacent to Center Park. This provides space and facilities for a wide range of community activities. There is an attached 18-car garage in Center Park, which is useful for residents with certain more limiting physical conditions.

Walter B. Roberts Manor

The only project for the blind under HUD programming was opened in 1969 in Omaha, Nebraska. It's a small, 42-unit building developed under the 221(d)(3) program in Omaha. The local Association for the Blind sponsored this building, which is not design modified in any way to accommodate blind persons. The only items adaptive to the needs of the blind are pieces of Dymo tape placed next to the elevator buttons, and the washer and dryer keys with letters punched out in Braille. Names on mailboxes and on doors are punched out on the tape in English. The building, in essence, represents the philosophy that the blind should adapt to the techniques of the sighted, but the question could be raised whether this applies in a building devoted largely to the blind and the partially sighted. Thus, the further question is: Are there disabilities which, when grouped, produce additional difficulties in living?

Highland Heights

Highland Heights opened in 1970, under the aegis of the Fall River, Massachusetts, Housing Authority, and with the very strong assistance of the adjacent Hussey Hospital. This rehabilitation hospital helped provide an orthopedic orientation to the 208-unit building that has made it almost the housing component of a very effective, if older, medical facility. The two buildings are connected by an underground causeway, but more important, the hospital provides staffing for the building's clinic and medical services across a wide range for the residents. In turn, hospital patients, once they are rehabilitated, can be admitted to the building when vacancies occur.

Highland Heights has all the features of Center Park, but also provides handrails; lowered toilet seats convenient for wheelchair users; correctly located phone jacks; external elevator indicators; convenient light switches; smooth internal walls; adequate sleeping areas in the efficiencies; and excellently designed public space.

Highland Heights also provides a unique emergency feature: When the emergency switch in the bedroom or bathroom is activated, a light goes on outside the apartment, a bell rings on the floor, and gongs go off in the ground floor clinic and the Rehab Clinic at the Hussey Hospital.

Even more significant than the design is the operation of the facility. It has become a focal point of community activity around the needs of the handicapped and elderly, with a host of community services pouring in to meet resident needs. So, for instance, the Fall River Council on Aging is located in Highland Heights. Hot meals programs, surplus commodities, aid referrals, all have emerged as a result of this presence. But in addition, the District Nursing Service, a Golden Age Club, social workers, therapists, a sewing group, arts and crafts, beauty and barber shop, choral and music groups, all have become part of resident services, whether provided by the Hussey Hospital, outside agency service, volunteers, or simply the normal social interaction that appears in a healthy social organism. Thus, despite the unusual range of physical limitations of the residents, their effective functioning is at a high level because of fine building programming.

New Horizons

This 100-unit project opened in July, 1972, in Fargo, North Dakota. The architects visited all the prior projects, analyzed all the design problems covered previously, and came up with what probably is the best physical structure for the handicapped in the United States. Rooms are ample, bathrooms are well laid out, shallow sinks are arranged so wheelchairs can be moved underneath comfortably; three central tub rooms are available for those who need assistance in bathing; smoke detectors and sprinkler system are installed; wall ovens provide a side-hinged door and a pull-out shelf

below the door; and there is a pull-out cutting board, with a mixing bowl cutout. Only the elevators and the rehab room are small. Community facilities in the building are excellent and there is a full joint kitchen, from which a number of residents have hot meals delivered at lunch time, through a nearby meal service. A shopping center exists across the highway in front of the building. The parking area is entirely covered.

In brief, the building was designed primarily with the wheelchair bound person in mind, and, except for elevators, is a profound success.

Independence Hall

This is the largest of the projects for the handicapped, with 292 units on two floors. Opened in January, 1973, in Houston, Texas, it is a two-story, sprawling complex on a 10-acre site with garden-type, interconnected buildings, in the form of three diamonds, linked at their sides. Two long double ramps, centrally located, lead to the second floor, but there are also two small elevators at each end of the complex. The project includes lever door handles, floor plate openers at several locations for public doors, drive-in showers with support bars, wide doors throughout, emergency buzzer system to the main office, shallow kitchen sinks with space underneath for wheelchairs, low kitchen shelving, under-the-burner oven, crafts and workshop space, library, and sewing room.

Independence Hall is unique in that Goodwill Industries sponsored the project. It has close ties to the Goodwill plant. Many employees are housed and, most significant, everyone who runs the building is handicapped, including administrative, clerical, and maintenance staffs. There is also a strong link to available hospital and medical services, to say nothing of the normal social services utilized by the Goodwill process.

Creative Living

This building in Columbus, Ohio, is unique as the only one designed for paraplegics and quadriplegics. Built on land leased from Battelle Memorial Institute for $1 a year, this Section 236 project opened in October, 1974, and is a barrier-free 18-unit one-story building designed for the wheelchair-bound person. Doors are pressure-activated; there are special plumbing features; kitchen cabinets are 30 to 40 inches off the floor; electrical outlets are about 30 inches high; door openings are never less than 32 inches wide; clothes racks no higher than 48 inches.

One section of the building has a dayroom for students from the adjacent Ohio State University Medical School who work as attendants on an hourly basis, serving the mobility needs of the residents. These range from toileting and dressing in the morning and evening to turning at night to avoid bedsores.

Creative Living is a by-product of a particularly fine Department of Physical Medicine at Ohio State. Here paraplegic and quadriplegic patients are rehabilitated, use powered wheelchairs and speaker-phones, press buttons, dial phones, dictate letters, and perform all kinds of light office and daily activity. It is a tribute to brains, ingenuity, persistence, professional skill, and above all, superhuman faith.

d. Research into housing the handicapped

The existing supply of housing units for the handicapped, most of which are included in projects for the elderly, only begins to meet the housing needs of our handicapped population. Furthermore, research is needed to develop an understanding of the needs which the handicapped have in making use of the built environment. There also is a need to evaluate the function and designs of the units already constructed in meeting the housing needs of the handicapped. HUD's Office of Policy Development and Research (PD&R) has begun a program of research along both lines.

The lack of housing which meets their needs denies handicapped persons the independent life they want and are capable of living. This situation is exacerbated by restrictions on the use of outdoor space and a lack of accessibility to public transportation.

PD&R has undertaken several research efforts leading to a built environment that will allow the handicapped person to be integrated into society to the extent he or she desires and is capable of, with a minimum of architectural barriers or other man-made impediments. HUD has sought and received the advice and guidance of the Department of Health, Education, and Welfare, the Architectural and Transportation Barriers Compliance Board, the Committee on Barrier-free Design of the President's Committee on Employment of the Handicapped, the American Institute of Architects, and the National Society for Crippled Children and Adults.

To date, PD&R has completed two fairly recent studies. The first took place in one of the eight HUD-sponsored buildings for the handicapped, Highland Heights in Fall River, Massachusetts. The Fall River Housing Authority completed a study in 1972 of the effects of residence in a sheltered but noninstitutional housing situation on their population of severely handicapped adults. Results showed that such an environment proved to be a positive experience, and that over the short run residents improved in terms of morale and physical functioning.

Because HUD believes that these individuals could better utilize environments thoughtfully designed to accommodate their limitations, the American Society of Landscape Architects Foundation (ASLAF) was awarded a two-year $107,000 contract to develop a guide to barrier-free site design. The results of this study are available from HUD and the Government Printing Office in two separate volumes.

One is an illustrated manual for environmental designers faced with the need to design accessible sites for both public and private facilities. This guide,

Housing Projects for the Handicapped

Name	Location	Sponsor	Year Opened	Cost	Size/ Group	Specially Served
Vistula Manor	400 Nebraska Avenue Toledo, Ohio 43602	Toledo Metropolitan Housing Authority	1967	$3,800,943	164	Handicapped and elderly
Pilgrim Tower	1233 South Vermont Avenue Los Angeles, Calif. 90006	Pilgrim Lutheran Church of the Deaf	1968	$1,723,000	112	Deaf and hard of hearing elderly
Center Park Apartments	825 Yesler Way Seattle, Washington 98104	Seattle Housing Authority	1969	$2,596,421	150	Handicapped and elderly
Walter B. Roberts Manor	1024 South 32nd Street Omaha, Nebraska 68105	Omaha Association for the Blind	1969	$ 422,900	42	Blind and partial sighted elderly
Highland Heights	1197 Robeson Street Fall River, Mass. 02722	Fall River Housing Authority	1970	$2,942,204	208	Handicapped and elderly
New Horizons	2525 North Broadway Fargo, North Dakota 58102	Fargo Housing Authority	1972	$1,947,875	100	Handicapped
Independence Hall	Airline Dr. at Burress St. Houston, Texas	Goodwill Industries	1973	$3,179,800	292	Handicapped and elderly
Creative Living	445 W. 8th Avenue Columbus, Ohio 43215	Creative Living, Inc.	1974	$ 333,100	18	Quadri- and paraplegics

Barrier-free Site Design, covers the design and planning of site features such as parking lots, walks, ramps, play areas, pools, street furniture, lighting, signage, and restrooms.

The second, available late this fall, is a compendium of existing design criteria and construction standards used in the project. It provides to the designer comprehensive information about existing barrier-free related legislation, standards, guidelines, etc.

PD&R also currently has several projects related to the needs of the disabled under way. In 1961, the American National Standards Institute (ANSI) affirmed a set of standards (ANSI A117.1) for making buildings accessible to and usable by the physically handicapped. Since that time the HUD Minimum Property Standards, Public Law 90-480, and many state accessibility laws and local building codes have specifically referenced the ANSI Standard or have been based upon it. However, as stated in a letter to HUD from the President's Committee on Employment of the Handicapped, one of the sponsors of the original standard, "... it is widely recognized by professional designers and by administrators that the document is inadequate in defining accessible multifamily housing. Kitchen, bathroom, and living space design specifications are not included. Code authorities, legislators, housing developers, and city planners are constantly requesting such information. . . ."

In response to a request from the President's Committee and from the National Society for Crippled Children and Adults—the sponsors of the original standard—HUD agreed to begin developing a revised and expanded ANSI standard which would cover public buildings, dwelling units, and related exterior spaces. The School of Architecture at Syracuse University was chosen to administer the program of research and testing necessary for developing the new standard.

The results of the two-year, $256,000 effort which will be completed in June, 1976, will be a performance standard that emphasizes the concept of adaptability. It will reflect the state of the art in accessibility not only in the United States, but also in the countries in Northern Europe, which have a great deal more experience than the United States in housing for handicapped persons and which have met with great success in the use of performance standards and in the integration of the handicapped into their community. The new standard will be submitted to ANSI for adoption and to HUD for inclusion in the Minimum Property Standards.

The new ANSI Standard also will incorporate the results of the recently completed site design study by the American Society of Landscape Architects Foundation.

The first year's work on the ANSI project resulted in a comprehensive state-of-the-art review which is currently being evaluated for possible publication.

St. Andrews Presbyterian College came to HUD with a problem and with a potential solution to be tested. Located on a barrier-free campus in Laurinburg, North Carolina, the college has had considerable experience and success in educating the severely handicapped and in placing them in jobs. However, many of their graduates were unable to accept the positions offered because of a lack of suitable housing within commuting distance. The

school adapted four standard mobile homes from the surplus disaster relief stock for occupancy by handicapped students. At the end of the two-year $204,000 project, a fifth demonstration unit incorporating as many of the features as feasible will be available for display.

The project team is giving special attention to safety factors, and is also doing psychological testing to determine the effects of this sudden increase in independence and in responsibility upon persons who previously led relatively sheltered, protected lives. At first the students living in the demonstration units experienced what Dean Rodger Decker, project director, describes as a "halo effect." Because almost all of the St. Andrews students live in campus dormitories and the four students in the demonstration mobile homes are living independently, the handicapped students were among the most popular on campus! All the students are delighted with their homes and have experienced little or no problems with them.

Fall River is currently undertaking a three-year, $97,000 follow-up study which increases the size of the survey sample so that it can be subdivided by type and degree of disability. This phase of the research will seek to determine if persons with different types or degrees of disability benefit differently from residence at Highland Heights. The results of the study will enable managers to develop a rational set of tenant selection procedures for environments such as Highland Heights. An additional, companion piece of research supported by HEW is also looking at the original sample of respondents over a five-year period to see whether the short-term results found by the initial study continue over longer periods of time.

HUD intends to continue its research on improved housing and community environments for the handicapped. A study of the effects of integrating the handicapped into all housing, not just elderly housing or buildings designed for the handicapped, is planned for the next two years. An evaluation of small group homes for the developmentally disabled will also be sponsored. In addition, HUD hopes to sponsor demonstrations and evaluations of the design guidelines developed by the previously described American Society of Landscape Architects Foundation study.

e. HUD Minimum Property Standards (MPS) for handicapped persons

Although Public Law 90-480 was implemented in HUD's programs by Part 40, Title 24 of the Code of Federal Regulations and by revisions to handbooks for various programs—Low-Rent Public Housing, College Housing, Open Space and Neighborhood Facilities—the documents most affecting the design and construction of HUD-related residential projects probably are the Minimum Property Standards.

Through the Minimum Property Standards HUD requires mortgage-insured multifamily projects to be accessible to the physically handicapped on the same basis as public housing, even though Public Law 90-480 does not apply to such projects. Also, all housing for elderly must be accessible.

The mandatory MPS, consisting of three volumes, one for single family housing, one for multifamily housing, and a third for nursing and intermediate care facilities, are supplemented by a nonmandatory volume titled *Manual of Acceptable Practices.* These criteria are intended to provide a sound basis for determining the acceptability of HUD-associated housing. They are used by the Farmers Home Administration, Veterans Administration, and some military housing programs.

Originally the MPS were couched in prescriptive language and were directed to specific programs. In 1974 they were reissued. The new documents are written in performance language to allow greater design and construction freedom to meet local needs and to promote more innovative design. They now relate to building types rather than to specific programs. In this way the three new volumes were able to replace eleven sets of program-oriented standards. Hence, HUD does not maintain a separate book or set of criteria for projects of housing for handicapped persons. Material pertinent to design for handicapped persons is contained in all three books—depending on whether the building type used is a detached dwelling, row or apartment house, institutional type building, or other. This distribution of criteria is consistent with the conviction that handicapped individuals should not be isolated into separate projects especially designed for them, but that they should be integrated into housing for nonhandicapped families.

By not placing criteria for handicapped persons in a separate MPS, HUD obviated the need to repeat all of the criteria for construction materials and workmanship and much of the site and space planning and other design criteria which are the same regardless of the physical and mental attributes of a project's occupants.

HUD believes the distribution of specific criteria for handicapped persons throughout the three MPS's is more effective than making a single reference to American National Standards Institute A117.1 and stating that all facilities must comply with it. Thus where criteria for amount, size, and location of parking are given for family housing, the corresponding standards for handicapped persons are given. Where criteria for walks are given, corresponding special requirements for handicapped persons are given, such as maximum gradients and prohibition of steps for stepped ramps between a principal entrance and a vehicular unloading zone. HUD does not repeat criteria which are the same for handicapped and nonhandicapped persons. For example, slip resistant surfaces are required on all walks.

This arrangement permits HUD to invoke A117.1 for a specific feature when that standard is adequate and to set up its own criteria when it is not. A117.1 was written for public, not residential buildings, so it contains no data on kitchen design, showers, bathtubs, and such life safety features as number of exits, flame spread, or

emergency power. These items are detailed in the MPS.

Other criteria for handicapped persons in excess of material in A117.1 which are found in the multifamily MPS includes accessibility to beds, night lights, minimum hall widths for wheelchair users, prohibition of abrasive wall finishes, nonscald valves in showers, and emergency lighting systems. This material is supplemented by recommendations in the Manual of Acceptable Practices pertinent to space allocation for social, recreational, and other common functions, wheelchair dimensions, clearances in common dining areas for wheelchair occupants, and entrance facilities—automatic door opener, view panels, and vestibules. In short, HUD criteria are more complete and exhaustive than those given in A117.1 In addition, they are constantly being reviewed and updated to take advantage of the most recent technological advances, experience, and research—both foreign and domestic.

Department of Health, Education, and Welfare (HEW)

A. Authorization

HEW has no specific authorization to provide housing for the handicapped.

B. Purpose

Under the public assistance titles of the Social Security Act, grants to states are provided for financial assistance to needy families with children, and in Guam, Puerto Rico, and the Virgin Islands to needy aged, blind, and disabled for food and shelter, among other things. These programs are incidental to the other purposes of the acts quoted.

C. Eligibility

Financial assistance is available only to those eligible for the financial assistance under the public assistance titles. Only the staffs of Indian health facilities are provided housing.

D. Scope

No data are collected on the housing and living arrangements that arise incidental to these acts since the individuals involved make their own housing arrangements.

E. Standards

Under the assistance provisions of the Social Security Act, there are no minimum housing standards for recipients of the assistance, and there is no specific requirement that housing be accessible to the physically handicapped.

ANSI standards, supplemented by HEW criteria, are used to provide accessibility for the physically handicapped who may be living or working at the Indian health facilities.

Veterans Administration (VA)

A. VA Home Loans

a. Authorization

Chapter 37, Title 38, U.S. Code, contains the authorization for the VA Home Loan Program or, as it is most commonly called, the "GI Home Loan Program." The objective of the program is to assist veterans of World War II, the Korean and post-Korean conflict periods, certain servicemen, and unremarried widows of veterans to obtain credit for the purchase, construction, or improvement of homes on more liberal terms than is generally available to nonveterans.

b. Purpose

VA may guarantee or insure home loans made to eligible veterans for any one of these purposes: (a) to buy or build a home; (b) build a farmhouse on land he owns; (c) repair, alter, or improve a farmhouse or other dwelling he owns; (d) buy a one-family residential unit in an approved condominium housing project; (e) refinance a mortgage or other lien on a house owned by the veteran. VA may also guarantee loans for the purchase of new and used mobile homes.

c. Scope

Since the inception of the program in 1944, VA has guaranteed approximately 9,000,000 home loans for an aggregate principal amount exceeding $109 billion.

d. Eligibility

While VA may guarantee any loan to all classes of eligible veterans, it may insure loans made only to World War II and to Korean conflict veterans by lenders subject to state or Federal examination and supervision. In all cases the borrower must own and occupy, as his or her home, the housing unit securing the loan. The nature and condition of the unit must be suitable for dwelling, and the loan may not exceed a VA determined reasonable value of the property.

The applicant eligibility criteria for "GI Home Loans" is: (a) veterans of World War II or the Korean conflict who served on active duty 90 days or more and were discharged or released under conditions other than dishonorable; (b) veterans who served on active duty 181 days or more, part of which occurred after January 31, 1955, and who were discharged or released under conditions other than dishonorable; (c) any veteran in

the above classes with less service but discharged with a service connected disability; (d) unremarried widows and widowers of otherwise eligible veterans who died in service or whose deaths were attributable to service connected disabilities; (e) service personnel who have served at least 181 days in active duty status; (f) spouses of members of the Armed Forces serving on active duty, listed as missing in action, or as prisoners of war and who have been so listed 90 days or more.

e. Standards

VA has adopted as its construction standards the HUD Minimum Property Standards, One and Two Family Dwellings, 4900.1.

B. Specially adapted housing

a. Authorization

The authorization for the VA to assist certain disabled veterans in acquiring suitable housing units with special fixtures and facilities made necessary by the nature of the veteran's disability is contained in Chapter 21, Title 38, U.S. Code.

b. Purpose

The VA Specially Adapted Housing Program provides 50 percent of the cost to the veteran of the housing unit, land, fixtures, and allowable expense, not to exceed $25,000. The money may be used to assist in (a) construction of a suitable home on land to be acquired by the veteran; or (b) construction of a home on suitable land owned by the veteran; or (c) remodeling an existing home if it can be suitably adapted; or (d) application against an outstanding mortgage for a specially adapted home owned by the veteran.

In computing the amount of a grant payable to the veteran, the housing unit cost may include incidental expenses, such as connections or extensions to public facilities, customary attorneys, architect, loan closing, and other service fees. Restrictions on the use of a grant are: (a) if a loan is necessary to supplement a grant, monthly repayments and the cost of maintaining the housing unit must bear a proper relation to the veteran's present and prospective income; (b) the housing unit must be suitable for the veteran's special dwelling needs; and (c) the veteran's acquired interest in, or title to, the property must meet standards generally acceptable to informed real estate market participants in the locality of the property.

c. Scope

During the 27 years of the VA specially adapted housing program existence more than 13,500 veterans have been aided at an expense of approximately $154 million.

d. Eligibility

In order to be eligible for a specially adapted housing grant, a veteran must have a permanent, total, and compensable disability, based on service after April 20, 1898, due to (a) loss or loss of use of both lower extremities to an extent precluding locomotion without braces, cane, crutches, or wheelchair; or (b) blindness in both eyes, having only light perception, plus loss or loss of use of one lower extremity; or (c) loss of use of one lower extremity with residuals or organic disease or injury affecting balance or propulsion so as to preclude locomotion without resort to a wheelchair. It must be medically feasible for the veteran to reside in the proposed or existing housing unit and in the locality.

e. Standards

When it is determined that it is medically feasible for an eligible veteran to reside in a specially adapted home, the veteran is contacted by a representative from the local VA office who is a specialist in the field of specially adapted housing to counsel and make suggestions and recommendations to the veteran at every stage to help him/her obtain a specially adapted house. The counsel includes providing sample housing plans and helping the veteran get architectural services, contractors, bids, and any other related service necessary to assure that a satisfactory specially adapted house is provided. As a result of its experience with specially adapted housing, the VA has developed the following special requirements which, of course, may be modified to meet individual needs:

(a) At least two ramps suitable for egress, one of which shall be located so as not to expose the veteran to a potential fire hazard, such as placement necessitating passage through a kitchen or garage or utility room containing heating equipment. Ramps must be constructed of fireproof material, shall be permanently installed, shall be treated to prevent slipping when wet, and the slope shall not exceed 8 percent. The minimum width acceptable is 3 feet, 6 inches, and the railings must be provided if the height and length of the ramp indicate any question of a hazard. Each ramp must be headed at the top by a level platform which is freely accessible from the ramp. Ramp platforms must be generous in an area to allow for turning the wheelchair and equipped with protective railings if the height of the platform presents a potential hazard. There shall be no difference in elevation between the interior floor level and point of ramp entry.

(b) All doorways shall be at least 36 inches wide.

(c) Halls shall be a minimum of 4 feet wide.

(d) A garage or carport should be of sufficient width to allow unrestricted wheelchair maneuverability alongside the car.

(e) Passageways between the home proper and the garage or carport should be sheltered to prevent exposure of the veteran to inclement weather.

(f) At least one bathroom convenient to the veteran's bedroom should contain very generous floor areas providing free wheelchair maneuverability, with placement of all fixtures in a manner permitting the veteran unimpeded access to each fixture. Bathroom flooring material should be nonslip under both wet and dry conditions. Wash basins of the hung type, rather than pedestal, shall be affixed at a height enabling the wheelchair to ride below the fixture to allow close approach for washing and shaving convenience. Wash basin drainpipes should be installed with the view to minimizing the possibility of abrasions. A mirror at suitable level of use from the wheelchair must be provided and may be achieved by a lowered medicine cabinet to which the veteran is to have access. Faucets for the tub and shower also must be accessible from the wheelchair for water temperature control before, as well as during, immersion. Adequate thermostatic controls should be installed to avoid sudden change in the water temperature. Adequate grab bars, capable of bearing weight and conveniently placed, must be installed for the tub and shower. Stall showers must be large enough to allow for a built-in bench, if desired. There shall be no curb between the stall and bathroom (floor drain can be placed in a back corner of the stall), and the shower stall opening must comply with the width requirement. The toilet fixture or seat should be raised, if necessary, for the veteran's convenience; armrests, installed in a manner to support the veteran's weight in transferring, must be included, and provision should be made for a suitable back support. Where veterans have a decided preference for a shower installation, serious thought nevertheless should be given to a tub installation as well.

(g) All hot water pipes, steampipes, room radiators, or similar items which may constitute a hazard insofar as burns, abrasions, etc., are concerned, should be concealed or properly covered.

(h) Wall switches and electrical outlets should be within reach from the wheelchair—minimum 18 inches and maximum 48 inches from the floor. Fuse boxes, thermostats, and other utility and appliance controls should be within reach from the wheelchair. Windows should be operable from the wheelchair. Automatically operated garage doors are a great convenience. Direct control activated by key or button is more satisfactory than remote control by radio or light beam.

(i) An automatic smoke detector, which may be a single-station alarm device, shall be installed in each living unit near the bedrooms. Such detectors shall comply with the standards of the Underwriters' Laboratories Standard No. 168 for photoelectric type and No. 167 for the ionization type. Detectors shall be labeled indicating compliance with the above standards. All smoke detectors shall operate from the dwelling's electrical circuit without a disconnecting wall switch and be permanently mounted to a standard electrical outlet or junction box on or adjacent to the ceiling.

(j) Carpeting and rugs impede wheelchair maneuverability. Accordingly, installation of carpeting will not be approved as a general rule. Requests for waiver to permit installation of low pile, closely knit carpet will be considered on an individual basis. Such requests must be supported by a statement in writing from a VA physician as to the veteran's ability to maneuver on it or that it will not impede his/her mobility.

Department of Agriculture

The Farmers Home Administration (FmHA) does not have a housing program specifically for the handicapped. It does, however, administer three housing programs which may be included in any report on the status of issues and direction of housing for the physically handicapped. FmHA does not have records as to the number of physically handicapped individuals occupying individual or rental housing units financed by the agency.

A. Low to moderate income housing loans

a. Authorization

These loans are authorized under Section 502 of Title V of the Housing Act of 1949. The objective of this loan program is to assist rural families to obtain decent, safe, and sanitary housing and related facilities. These loans are made to eligible applicants to buy, build, or improve homes located in rural areas; to provide necessary and adequate sewage disposal facilities for the applicant and his family; and to buy a site on which to place a dwelling for the applicant's own use. Housing debts may be refinanced only under certain circumstances.

b. Purpose

Dwellings financed under this program for a family with low or moderate income must be modest in size, design, and cost. In addition, the applicant must be without sufficient resources to provide, on his own account, the necessary housing or related facilities and be unable to secure the necessary credit from other sources upon terms and conditions which he reasonably could be expected to fulfill.

c. Eligibility

To be eligible for a Section 502 rural housing loan, the applicant must be the owner or when the loan is closed become the owner of a home in a rural area. He must also be a citizen of the United States or reside in the United States after having been legally admitted for permanent residency, have adequate and dependably available income to meet his operating and family living expenses including taxes, insurance, maintenance, and repayment on debts including the proposed loans. Interest credits may, under certain conditions, be granted to lower income families which will reduce the

effective interest credit rate paid to as low as one percent depending on the amount of the loan and the size and income of the family.

d. Scope

During fiscal year 1976, FmHA expects to process more than 100,000 initial and subsequent Section 502 loans for approximately $1.927 billion compared to last year's $1.9 billion.

B. Very low income housing repair loans

a. Authorization

These loans are authorized under Section 504 of Title V of the Housing Act of 1949, as amended.

b. Purpose

The loans give very low income rural homeowners an opportunity to make essential minor repairs to their homes to make them safe and to remove health hazards to the family or the community. This could include repairs to the foundation, roof, or basic structure as well as making the housing more convenient for a physically handicapped person. Funds may be included in these loans to provide a water and waste disposal system for the dwelling.

c. Eligibility

The maximum loan under this program is $5,000, which can be repaid in up to 20 years. The interest rate is one percent per annum. Applicants must own and occupy the dwelling and be without sufficient income to qualify for a Section 502 loan yet must have sufficient income to repay the loan.

d. Scope

FmHA has an allotment of $20 million available for such loans and has obligated approximately $4.5 million in loans to approximately 2,500 applicants during each of the past two fiscal years.

C. Rural rental housing loans

a. Authorization

FmHA is authorized under Section 515 of Title V of the Housing Act of 1949 to provide economically designed and constructed rental housing and related facilities suitable for independent living or rural residents.

b. Purpose

The loans can be used to construct, purchase, improve, or repair rental or cooperative housing. Housing may consist of apartment buildings, duplex units, or individual detached houses. Funds may also be used to provide recreational and service facilities appropriate for use in connection with the housing and to buy and improve the land on which the buildings are to be located.

c. Eligibility

Applicants may be individuals, consumer cooperatives, trusts, nonprofit corporations, profit corporations, associations, state or local public agencies, partnerships, or limited partnerships. With the exception of state or local public agency, they must be unable to provide the housing from their own resources or with credit obtained from private sources. Applicants must, however, be able to assume the obligations of the loan, furnish adequate security, and have ability to provide management and to maintain and operate the housing for the purpose for which the loan is made.

d. Scope

There is an authorization for $146 million to be expended for rural rental housing loans in fiscal year 1976 as compared to $296 million in fiscal year 1975.

Department of Defense

A. Authorization

Annual Military Construction Authorization Acts

B. Purpose

The Department of Defense (DoD) programs for housing may be divided into two general categories, housing for bachelor personnel and housing for married personnel.

Housing for bachelor personnel enlisted and commissioned, is not designed to be accessible to the handicapped. Public Law 90-480 excluded from its provisions "... any building or facility on a military installation designed and constructed primarily for use by able-bodied military personnel ..." and, as these facilities are designed and constructed exclusively for able-bodied military personnel, they are not covered by the law.

Housing for married personnel also is not specifically designed to be accessible to the handicapped. The ratio of handicapped to nonhandicapped living in military family housing may be somewhat less than that of the general population since at least one member of all such families would be an able-bodied military person. Even the ratio of handicapped to nonhandicapped among military dependents would normally be less than the general population. This is so because the retirement age for military personnel ranges from under forty years to about the mid-fifties. Thus, the aged as a group are not

found among the families occupying military housing. Nevertheless, there are some handicapped individuals among military families. When a family with a handicapped member is assigned to a DoD owned house, DoD normally handles any indicated modification to the house at that time. This is of course an option which is available to the military which might not be economically feasible for a family seeking to buy a private dwelling on the open market.

C. Eligibility

Military housing programs are limited programs serving very specialized populations. They are, therefore, not directly comparable with the overall housing market.

D. Scope

The scope of these programs varies from year to year depending on their overall program priority. The fiscal year 1976 program will have about 3,000 family units and the bachelor housing program foresees the construction of new housing spaces for approximately 26,000 personnel. Future programs are expected to be comparable. However, a gradual shift of emphasis away from new construction to modernization and improvement of existing older units is expected.

Normally DoD does not build houses for civilian employees. In the case of military necessity where a key or essential civilian employee is required to live on a particular installation, that employee may be assigned to a military house. Those situations do not frequently occur.

E. Standards

General application of the principles of design for the handicapped to the military housing programs would result in less than average, and, in the case of bachelor housing, no benefit to the handicapped.

However, there are a number of design proposals that have been put forth to assist both the handicapped and nonhandicapped individual. Typical of these would be the elimination of door knobs and latches in favor of levers or other devices more easily usable by all persons. This, a very productive area for assistance to the handicapped, exists in the promotion of such design for all housing.

APPENDIX B*

*From: McGaughey, Rita, Position paper on "Adequate Residential and Community Programs for Persons with Disabilities," National Easter Seal Society for Crippled Children and Adults, March 1976.

ATTACHMENT A

Table A

Federal Programs Financing Services and Housing to Handicapped

	Payments to Service Providers	Direct Payments to Handicapped	State Plan Required	Housing Assistance	Subsidized	Private Sponsors	Private Nonprofit Sponsors	Congregate Housing	Special Design	Rural Only	Special Project Grants	Developmentally Disabled (Mental)	Physically Disabled	Mentally and Physically Disabled	Elderly Handicapped Only	Formula Grants to States	Delivered Services, Payments for	Facilities Construction
Developmental Disabilities Services & Construction Amendments 1970			X	X							X	X				X	X	X
Developmental Disabilities Act 1975 (Pending)			X	X							X	X				X	X	X
Rehabilitation Act 1973			X								X			X		X	X	X
Older Americans Act, III	X		X												X		X	
Model Projects on Aging	X										X				X			
Grants, Nutrition Program	X		X												X		X	
Title XX, Social Security Act			X									X	X	X		X	X	
Social Security, Disability Insurance		X										X	X	X				
Social Security, Vocational Rehab. Service		X	X											X				
Public Assistance, Social Services			X	X										X		X	X	
Public Assistance, Maintenance		X	X											X				
Supplemental Social Security		X		X										X				
Medical Assistance Program–Medicaid	X													X				
Medicaid–Hospital Insurance	X			X										X				
Medicare–Supplemental Medical Insurance	X													X				
Housing & Urban Development Act 1974 Block grants	X										X			X		X	X	X
Public housing				X	X			X	X									
Section 8				X	X	X	X	X	X			X	X	X				
Technical Assistance				X	X				X					X				
Research & Demonstrations				X	X	X	X		X		X							
Section 202				X	X		X	X	X			X		X				
Section 231				X		X	X	X	X					X				
Section 235				X	X	X	X		X					X				
Seed Money Advances				X	X	X	X							X				
Farmers Home Administration 515 loans				X	X	X	X		X	X				?				

Table B

Services Provided Handicapped by Federal Programs

PROGRAMS / SERVICES	Diagnosis	Evaluation	Treatment	Personal Care	Day Care	Domiciliary Care	Spec. Living Arrange.	Training	Education	Sheltered Employment	Recreation	Counseling	Protective Services	Information & Referral	Transportation	Vocational Training	Voc. & Rehab. Devices	Hospitalization	Corrective Surgery	Therapeutic Treatment	Treat. Mental Disorders	Maint. during Treatment	Interpreter Services	Employ. Opportunities	Mobility Train.-Blind	Social Services	Homemaker Services	Health Services	Home Health Aid	Chore Services	Friend. Visiting	Telephone Reassurance	Asst. in Obtain. Hsg.	Adapt. Hsg. & Construct.	$1,500 Homeowner Repair	Nutrition-Meal Delivery	Home Del. Meals	Foster Care	Home Mgmt. & Maint.	Adult Day Care	Health Support	Family Planning	Home & Money Mgmt.	Food, Shelter, Clothing	$250 Home Repairs	Income	Lab & X-rays	Skilled Nursing Home	Extended Care	Outpatient Services	Physician	Counsel to Home Purchas.	Congregate Housing	Escort Services
Develop. Disabil. Act 1970	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X																																					X	
Develop. Disabil. Act 1975	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X																																					X	
Rehabilitation Act 1973	X	X							X		X	X		X	X	X	X	X	X	X	X	X	X	X																													
Older Amer. Act. III		X							X					X	X									X		X	X	X	X	X	X	X																				X
Model Projects on Aging											X	X		X	X												X	X						X	X																	X
Grants for Nutrition											X	X		X	X											X									X	X																
Title XX, Soc. Sec.								X				X	X	X	X									X											X		X	X	X	X												
Soc. Sec., Vocat. Serv.	X	X							X		X	X		X	X		X	X	X	X	X	X	X	X	X																												
Public Asst. Soc. Serv.																										X																											X	
Public Asst., Maintenance																																																						
Supp. Soc. Sec.																																																					
Med. Asst. Medicaid			X															X										X																									
Medicaid, Hosp. Ins.																		X																																			
Medicare, Supp. Med. Ins.																		X																																			
Housing Block Grants																										X		X																									
Public Housing																																																				X	
Section 8																																																				X	
Research and Demonstra.																																																				X	
Section 202																																																				X	
Section 231																																																				X	
Section 235																																																				X	
FmHA - 515																																																				X	
106 - HA74																																																					X	
Soc. Sec., Disability Ins.																	X																																				X	

SERVICE DELIVERY SYSTEMS

Awareness Paper Prepared By

Donald Stedman, Ph.D.
University of North Carolina
Chapel Hill, North Carolina

TABLE OF CONTENTS

Page

Introduction 351

Current Issues 351

Current Service Systems 354

Existing Programs 354

Legislation 357

Collaborative Activity 358

Three Critical Features of Service Systems 359

Problems and Recommendations 360

New Directions 366

References 367

Acknowledgment ---------- 368

ACKNOWLEDGMENT

The White House Conference on Handicapped Individuals wishes to thank the following individuals who have contributed significantly to this document:

Mrs. Marcia Burgdorf, Development Disabilities Law Project, University of Maryland

Ms. Eunice Firoito, Mayor's (N.Y.C.) Office of the Handicapped

Dr. James Folsom, Rehabilitation Medicine and Surgery, Veterans Administration

Lex Frieden, Houston University

Mrs. Essie Morgan, Socio-economic Rehabilitation and Spinal Cord Injury Service, Veterans Administration

INTRODUCTION

For nearly 200 years this country has been attempting to devise an effective program of services for handicapped individuals in the communities of America. However, it has only been since 1950 that significant strides in the direction of comprehensive services have been taken. It has only been during the last decade that notable achievements have been reached.

Part of the progress has been made because national attention has been drawn to the nearly 25 million persons in our society who have special needs due to some handicapping condition. Much of the gain has been a result of expanded research in the area of human development and rehabilitation. A large amount of the success is due to comprehensive approaches to health, social and educational problems and issues from the national level. Major generic programs such as social security, the poverty program, economic development, comprehensive health and insurance, and programs designed to improve the quality of life all help identify and reduce the incidence and impact of handicap on the person and society.

Special federal and state legislation, and consequent service program development, from the time of the Kennedy Administration to the present day, notably the Comprehensive Mental Health/Mental Retardation laws, the Veterans Administration laws, the Economic Opportunity Act, the Rehabilitation Act, the Civil Rights Act, the Maternal and Child Health laws, the facilities construction laws, and the Developmental Disabilities Act, have created a fabric of activity, yet uncoordinated, which sets the stage for effective action.

There is still substantial progress to be made, especially in the area of the integration of human services at the local level, but the momentum of the 1960s and 1970s make our 1980 goals and objectives more attainable. The key will be the extent to which consumer, provider, professional and bureaucratic structures can develop and implement effective plans and accountable systems of service and evaluation.

This paper is addressed to (1) the delineation of the critical dimensions and issues in the area of service delivery systems for handicapped individuals, (2) a specification of current service activities, and (3) proposals designed to stimulate the development of issues and consequent specific recommendations for national deliberation on the matter.

The author wishes to acknowledge the contribution and cooperation of Dr. Ronald Wiegerink in the development of this paper.

CURRENT ISSUES

In every field there are critical dimensions and issues which must be identified in order to develop conceptual and definitional paramenters for the problem. A review of current issues in the field of service to handicapped persons would include the following points:

1. *General services versus specialized services.* There is a continuing debate on whether specialized services at the local level are the best strategy for delivering services, either for prevention or treatment of handicapping conditions, as opposed to the augmentation of the existing general or traditional services such as health, education, social services and rehabilitation. Consumer advocates have been let down for years by the generic service components, especially at the state and local level, where priorities assigned to the development and delivery of services to the handicapped have been transient at best. Only recently, through the developmental disabilities movement have agencies begun to integrate the legal and legislative structure of state and local service program mandates. Categorical legislation, categorical funding, and special visibility for services and service structures for handicapped individuals continues to be debated.

2. *National versus local delivery systems.* A current major concern is focused around the matter of the appropriate and prime focus for the service delivery effort. Some would increase the effort at the national level in order to generate state and local services. Others would provide funding in bloc form to state and local structures in order to emphasize the proper focus of the responsibility and accountability for effective services for all people. This shift from national to state/local emphasis has moved along the continuum from one extreme to the other over the last 30 years with the current momentum shifting toward the prime responsibility for service at the state/local level.

3. *Consumer/provider input into planning and service delivery systems.* The recent rise of

consumerism and advocacy has provided for greater input for consumers and consumer representatives into the plans and activities of services for handicapped individuals. Heretofore, bureaucratic structures and professional groups "called the shots" and services were often fragmented and inappropriately emphasized as a consequence. However, there is continued concern, some rightly based, on the part of government and private officials and service providers that the influence of consumerism is not sufficiently measured or balanced by the realities of economics and legal constraints to respond sufficiently to local needs. This dimension of consumer/provider salience or impact in the area of planning and service delivery continues to be a major issue and should be addressed.

4. *Cost/social benefit.* The increased cost to the community of inadequate services to large segments of the population have led to a rationale that services to handicapped individuals is in the best interest of the total community and reduces the loss of productivity suffered by the community when large numbers of individuals are unable to be personally or socially productive. Again, the increased consciousness at all levels of the cost of public and private human services has brought into question the proper scope and strategy for delivering services to handicapped individuals. We have yet to see compelling cost benefit studies which provide sufficient data forservice program development. Most agree that social benefits flow to the individual and to the community from rehabilitation and other types of services. However, the cost/social benefit dimension remains largely unexplored but in great need of articulation in order to "shore-up" the advocacy and program development efforts on behalf of handicapped individuals.

5. *Evaluation and planning.* The focus has shifted from simply quantity of services to quality. Evaluation becomes more important than ever. The basic question remains, evaluation for what? By whom? The planning and program development cycles at the local level continue to omit pre-planned evaluation components and therefore deprive us of effective long range plans where evaluation of existing programs can lead to program improvement, the identification of new needs, and a comparison of alternative strategies for delivering services so that service effectiveness and cost benefit data could be derived. A concentration on evaluation as opposed to monitoring and auditing is felt by many to be overdue.

6. *Non-categorical versus the categorical maintenance of services for handicapped individuals.* The attempt to cross-categorize (or decategorize) training and service programs has met with stiff resistence from categorical advocates and the legislative and legal structures of the past which remain largely categorical in nature. The attempt to move toward non-categorical approaches to service delivery has been motivated by possible reduction in cost through this strategy and an attempt to unify and strengthen the varieties of special interest groups and specialized services that have arisen over the years under categorical flags. This ecumenism is best displayed in the planning and advocacy objectives of developmental disabilities councils and is found recently in the emergency of clusters of private and professional special interest groups who are increasing their potential for legislative pressure and improvements in community awareness through non-categorical or multi-categorical approaches. The effect on service delivery systems is obvious and should be considered.

7. *Manpower and quality control.* No current or proposed service system can operate long without the manpower necessary to deliver and evaluate the services. There is a lag between the planning and implementation of service programs and the planning and implementation of training activities which needs to be brought into phase. Increasingly the matter of quality control (licensing, certification, etc.) have come under attack as barriers to improved quantity and quality of service as well as inadequate and ineffective methods of assuring the best available staff to deliver service to handicapped individuals.

The new expectation of education to provide all handicapped children with a public education commensurate with their needs and as close to the mainstream as possible, has called for new roles and training for professionals. In fact, these new roles are roles and training for professionals. In fact, these new roles are an "about face" from those that have been established over the past 20 years. Regular education must once again learn to provide for a wider range of learning and behavioral styles: special educators must learn to relate their instructional programs

to the mainstream to provide ready access for the students who make the necessary progress: school psychologists and other ancillary personnel must learn to focus on providing inclusion rather than grounds and support for exclusion; and administration must assume responsibility for providing a climate and the resources to support mainstreaming rather than the development of separate services.

8. *Research applications.* There continues to be a lag in the delivery of knowledge and techniques for prevention and effective intervention for handicapping conditions on the order of 10 to 15 years or more. We have not fully addressed, nor have we adequately explored, the alternative methods of moving the products of basic and applied research quickly into the service system for evaluation and application. The few demonstration networks available have not been widely replicated or transmitted and we are still faced with the problem of stimulating the interest and activity or organizations and individuals without the capacity to follow through with wide dissemination of new and effective strategies for service.

9. *Resource development.* State and local service program development activities are still largely conducted without benefit of adquate or comprehensive knowledge of available resources. The capacity of federal and state agencies and other sources of economic and manpower resources are still not reaching the communities with the array of backup supports and implementation tools already available that could be applied to the development and delivery of services to handicapped individuals. Of particular note is the whole area of social security resources applied through state and local agencies. These programs often appear to be unintelligible and inaccessible pockets of resources to the average consumer or local official. Revenue sharing, specialized federal and state legislation, the utilization of various education, health and social services funds still largely elude the aspiring program developer.

10. *Public awareness/education.* Lack of adequate understanding on the part of the general public and in sufficient education to grasp and participate in the development of service systems at the local level remain fundamental barriers to progress toward alleviating the problems of handicappped individuals. Renewed efforts in the area of public education and public awareness programming must be initiated in order to more to the point of effective needs assessment and community mobilization on behalf of handicapped individuals.

11. *Legal advocacy/legislation/follow-through.* The use of legal advocacy has been prominent since 1954 on behalf of special subgroups within society. Class action litigation, consequent consent decrees and legislation have provided a "velvet fist" for advocates but remain largely unimplemented because of the lack of adequate resources and strategies for follow-through on the openings provided by the legal advocacy route. The development and delivery of services made possibly by the courts and accompanying legislative activity must be an area of concentration over the next few years in order to avoid losing the gains accomplished by this strategy.

12. *The integration of human service systems.* While this is not true for all States, frequently the competitiveness of agencies and special organizations has worked against the effective delivery of service at the local level. The coordination and linking of plans and implementation activities is a necessity if we are to have effective early identification and intervention programs, and if prevention and the maintenance of effective services are to take place. The versatility of service response remains low. Persons with multiple handicaps continue to "fall through the cracks" and comprehensive plans and service systems at the local level are still largely unknown.

13. *The mandate to education.* Numerous *right to education* law suits have made it clear that handicapped children can rightfully expect a public education with their non-handicapped peers. The landmark *Pennsylvania Association for Retarded Citizens* vs. *Commonwealth of Pennsylvania* case clarified the right of the mentally retarded to public education as close to the mainstream as possible. Some 50 other right to education suits across the country have demonstrated the educational needs of the handicapped and placed an overwhelming burden on public education to respond.

Recent legislation from Congress, the Education of All Handicapped Children Act of 1975 (PL 94-142) and state legislation in 48 states reasserts the right of the handicapped to a free public education. The Act provides funds for

this purpose. Unfortunately, the funds authorized from 5 percent (in 1970) to 40 percent (in 1982) of the cost of educating the average handicapped child. Even when added to the average pupil allotment this falls considerably short of the support needed to provide a quality basic education.

CURRENT SERVICE SYSTEMS

Existing programs

1. *Federal:*

By far and away the largest number and widest variety of special programs and agencies lie at the federal level. Within the major components of the executive branch, the Department of Health, Education and Welfare (HEW) constitutes the preponderance of activity.

The Office of Education, more specifically the *Bureau of Education for the Handicapped* (BEH), is the major component within HEW which is developing and delivering direct and indirect supports for educational research and development, training, demonstration, aid to states, and special projects activities.

The recent establishment of an Office of the Assistant Secretary of Health, Education and Welfare for human development (OHD) includes 4 components which deal directly with policy, procedures, program supports, contracts and grants, guidelines and other program development and direct service activities concerning program for handicapped individuals. The 4 components include the *Office of Child Development* (the home of Head Start), the *Rehabilitation Services Administration* (recently relocated from the Social and Rehabilitation Services area of HEW), the *Developmental Disabilities Office* (DDO) (implementing component for the Developmental Disabilities Act), and the *Office of Aging.* These 4 components in OHD present major national guidance systems, program development activities, monitoring and evaluation activities and advocacy roles within the federal level of government.

The *National Institute of Mental Health* (NIMH) is the most active and directly related federal agency component within the health services and mental health administration. In addition. the *Maternal and Child Health Services* component (MCHS) provides both direct service and training supports.

The National Institutes of Health include several components involved in direct research or support of research projects in the area of handicap, principally the *National Institute of Child Health and Human Development* (NICHHD) and the *National Institute of Neurological and Communicative Diseases and Stroke* (NINCDS).

The *Social Security Administration* and its various direct and indirect programs for individual support for handicapped persons constitutes a major organizational and financial base and source of program stimulation for handicapped individuals. The *Social and Rehabilitation Services* (SRS), including the *Medical Services Administration* and other components of SRS continue to provide a positive role, including a research and development activity, which supports rehabilitation and other social services activities.

Direct supports to counterpart state agencies by all of the above components constitute an extensive network of financial and programmatic activities in the area of handicapped persons. A recent report by the *Office for Handicapped Individuals* documents these activities.

In addition to HEW, the Departments of Justice, Housing and Urban Development, Labor, Defense, Agriculture, Commerce, and Transportation have small but often significant roles in the develpment and delivery of services, either directly or indirectly, to handicapped persons throughout the nation.

Each of the federal agencies indicated above is operating on one or more existing federal legislative mandates and also developing occasional combination programs which do not have a legislative base such as the recent development of child advocacy centers by sharing DDO, NIMH, and BEH monies.

In addition to the formal components of the executive branch of the federal government, there are at least 3 advocacy organizations. The *President's Committee on Mental Retardation* is a nationally visible organization which is a continuation of the President's Panel on Mental Retardation developed during the Kennedy administration. It was continued by executive order in the Johnson administration as the President's Committee on Mental Retardation. It has as its major objective the maintenance of national visibility of mental retardation and the

problems of developing and delivering services to the mentally retarded.

The *Office for Handicapped Individuals* in the Office of the Secretary of Health, Education and Welfare is a component created through the recently enacted Rehabilitation Act which conducts planning, service program projections, information dissemination, and other types of public education and public awareness activities across all types of handicapping conditions.

The *President's Committee on Employment ofs the Handicapped* is one of the oldest continuing Presidential committees related directly to handicapped persons. Established in 1958, it is concerned primarily with the development of public awareness of the employability and need for jobs and job training by handicapped adults. It is closely linked to the rehabilitation establishment and is an advocate for all types of handicapping conditions, including mentally and physically handicapped persons.

2. *State:*

According to the Management Services Associates Inc., June 1975 report traditionally states have followed four basic patterns of organization to provide rehabilitation and related services for the blind. As of June, 1975, there existed 20 states in a multi-agency configuration of a super agency (umbrella) type or on a smaller scale of diverse agencies (a mini-umbrella type); 15 states within another agency of government such as an education or welfare department; 8 states within another agency which is primarily concerned with general rehabilitation services; and 10 states in a separate agency of government such as a separate commission for the blind. Therefore, 20 states hardly constitutes "about half" of the states in the United States.

Occasionally it also includes a specialized mechanism similar to the Office for Child Development at the federal level.

The most prominent state agency is often the State Department of Public Education or Public Instruction, usually including a major component concerned with the education of exceptional children and the training of personnel to meet their special educational needs.

In addition to the above array of state agencies, a *Governor's Advisory Council on Developmental Disabilities* has been established in each state and territory as a result of the Developmental Disabilities Act of 1969. This Council has a planning, advisory and advocacy role in relation to state level planning and program development activities for all developmentally disabled persons in the state. A formula grant based on population and need is provided by the federal agency (DD) to assist the Council and its staff in the development and annual update of a comprehensive services plan for developmentally disabled persons. The plan is implemented through a combination of state and local service agencies in concert with other training and research and development organizations in the state, including public and private providers and higher education.

The Councils concern themselves primarily with the categories of mental retardation, cerebral palsy, epilepsy, autism and dyslexia, and other conditions leading to handicaps.

In most states there is a *Governor's Council on Employment of the Handicapped* which is a network component of the national President's Committee on Employment of the Handicapped. Their function is advisory to the Governor and is a within-systems advocacy organization dedicated to the advancement of jobs and job training and public awareness of the employability of handicapped persons in the state.

3. *County:*

Most counties throughout the United States have only generic agencies which focus on health, social services, education, and frequently, mental health, Organizational arrangements vary from one state to the other but there are usually very few specialized service delivery systems developed at the county level. There are comprehensive child development or mental retardation centers which have been developed from the 1963 federal legislation and consequent state legislation and laws. There are also a number of comprehensive community mental health centers funded in part by federal funds and the remainders by local, and private contributions. There are residential centers for handicapped including the mentally retarded, blind, deaf, and other types of programs, including correctional units. There are often diagnostic centers in addition to generic individual and group practitioner organizations providing local and county services. Additionally, there are centers for cerebral palsied persons.

4. *Private Sector*:

The development and delivery of services to handicapped individuals has been almost exclusively a *public* supported operation since the 1930s. Little in the way of large scale service programming can be attributed to privately supported organizations other than some volunteer agencies with specialized fund-raising activities tied directly to specific handicapping conditions such as epilepsy, cerebral palsy, multiple sclerosis, polio, and other types of specific disorders which are tied to specific debilitating outcomes.

Insurance companies have largely avoided investments in preventive or remedial service program development. The definitional problem, the difficulty of building parameters around client populations, and the difficulty of ascertaining cost and cost/benefit of services in this area have led insurance carriers and other profit-making organizations to regard the handicapped service delivery system business with great caution.

Profit making organizations steer clear of areas where definitions and population statistics are ambiguous and arbitrary. To the extent that we can clarify our problem we will attract support from insurance companies.

Organized labor benefits are increasing, especially through such major labor organizations as the AFL/CIO.* Specific statements are available from this organization with regard to current and proposed benefits for handicapped persons. Organized labor has been active in the rehabilitation business, both as a benefit to previously employed workers and as benefits to families of members of the union. The benefit package sought by most local unions has gone beyond the wages and hours issue to benefits such as support for handicapped members of the families of union members or the provision of child care, day care or residential care for handicapped union members or handicapped members of union members' families.

Voluntary organizations have played a major role in the development of public awareness of various handicapping conditions and the population of handicapped individuals. The National Association for Retarded Citizens (NARC), United Cerebral Palsy (UCP), the National Association for Mental Health, the Epilepsy Foundation, the National Foundation (March of Dimes), the United Fund, and to some extent the Red Cross, have been major positive forces in the development of public funds, collection of private monies and increase of public awareness with regard to the handicap problem. In many local programs volunteers representing the aforementioned agencies are available to assist in program services such as transportation, teacher aides and paraprofessional personnel, the development of local and state legislation, and participating in the political process which is usually necessary in order to mount service programs for handicapped individuals.

Public-private fund matching is to some extent a required activity inasmuch as many federal and state programs require matching funds, usually state or private funds. Aside from this matching requirement there are examples, especially in the job training area, which represent public-private funding activities. However, the public-private partnership approach has not been tried to any great extent in the area of service program development in the area of handicapped since the large amount of money necessary to address this problem is seen to be beyond the reach of just private investment. Also, there appears at this point to be little profit available except as might be derived from purchase of service strategies. Therefore, private-for-profit organizations steer clear of public-private lashups. Where proprietary organizations have entered into the provision of services,—such as for-profit nursing homes serving mentally disabled persons released from institutions—some controversy has been generated regarding the motives of such entrepeneurs and the quality of care delivered.

There are still a variety of problem areas which plague the development and effective delivery of services to handicapped individuals.

Eligibility requirements still either hold up or preclude direct services to many handicapped individuals either because of the lack of clarity, uniform administration or availability of professional personnel to make handicapped clients eligible.

Unraveling the mass of often conflicting information with regard to the availability of services and service supports often constitutes a

*The author is grateful for the assistance of Paul Burton Hammer in collecting information and materials on union and private insurance programs for handicapped, also for helping review current social security and SSI programs.

major problem for handicapped persons in accessing services even when they are available.

Resource development, ways of accessing available resources and reporting on their utilization, is often precluded or prevented in current or proposed service programs. A better method of providing information to current and proposed service programs with regard to available state and federal monies for program development activities is needed.

Evaluation procedures, both programmatic and individual, remain complicated and, often, are not accomplished because of the lack of available evaluators and trained persons to develop and interpret data necessary to evaluate the effectiveness of service programs.

The quality of management of local service programs still remains relatively low. Management training programs are needed that would provide competencies in planning, program development, program evaluation, resource development, development of adequate data base for decision making, the development and maintenance of client tracking systems, legal and advocacy activities, facilities construction and development, and development of liaison and replications activities.

Consumer participation in the planning and in the conduct of service systems is still a fairly limited practice. Great inroads have been made in that direction through mandated participation by consumers on major planning organizations such as the Developmental Disabilities Councils. However, training and effective utilization of consumers in the planning of service programs is still largely ignored or evaded. Parent training programs in local early education intervention programs are notable exceptions to this fact.

Legislation

Existing federal legislation is composed principally of the Developmental Disabilities Act, the Community Mental Health Centers Act, the Rehabilitation Act, the Early Education Assistance Act, the new educational aid-to-states federal legislation (S-6), the Elementary and Secondary Education Act, the Higher Education Act, and a variety of remaining comprehensive health bills and social security amendments. These constitute the basic platform from which current and proposed legislation is flowing.

The major problem at this point is not necessarily new legislation or the continuation of existing legislation but the development of adequate funding through appropriations for the effective implementation of the laws we have.

Recommended legislation would probably center around a single *National Handicapped Persons Act* which would provide the guidance and the funding, together with matching state and local monies, for a national network that would include the necessary components to provide for a comprehensive, integrated service delivery system at the local level. This would necessarily include an integration of the research and development, training, technical assistance, planning and special projects that would be necessary to assure the continued updating as well as evaluation of such a service delivery system.

The prior condition required to the establishment of such a National Handicapped Persons Act, and the consequent national network of services, would be the establishment of a set of national goals and objectives, which would set the directions for the implementation strategies and the evaluation of the national network of services. This might well flow from the activities of the White House Conference on Handicapped Individuals.

In addition, more attention should be paid to the development and implementation of a national network that would respond to the *multiple* needs of individual clients to be served by the comprehensive system. Coordination and collaboration of centralized, comprehensive and cross-cutting planning processes at the state and local level would be necessary. The regulations and guidelines developed in relationship to the legislation should be sufficiently flexible to allow for regional and local variation to meet special needs. Similarly, there should be a reinforcement schedule provided for federal, state, and local agencies to coordinate and integrate their services rather than to remain competitive.

In conjunction with new national legislation, states should concentrate on the development of *state legislation* such as Equal Education Opportunities Acts, the creation of *legislative commissions* on handicapped individuals, the development of *coordinating units* to cut across the executive branch of state government, and the development and implementation of *multi-*

county technical assistance systems to back up regional and local human services agencies.

Collaborative activity

There are increasing signs of cooperation and collaboration, within and between levels of government.

Federal agencies, Regional HEW offices, state agencies and local programs are engaged in various degrees and types of planning, evaluation, service, training, demonstration and technical assistance activities.

Table 1 lists examples of inter-agency cooperation which provide models or examples that there can be cooperation and that some agencies are doing it now.

For example, federal-federal interations are taking place around the issue of serving handicapped children through the Head Start program. The Office of Child Development and the Bureau of Education for the Handicapped (OE) are joining forces to establish regional training centers for Head Start staff to make services available to pre-schoolers who are handicapped.

At the regional level, HEW Regions VIII and IX are collaborating on the development of a client tracking system, funded by the Developmental Disabilities office.

At the state-local intersection, state Developmental Disabilities Councils, using federal funds, are establishing local demonstration service projects to stimulate service and advocacy activities for developmentally disabled persons.

This kind of meshing is the exception rather than the rule and should be a regular feature of agency/program development and activity.

Agencies need reinforcement for such cooperative program activity.

Table 1. Examples of Shared/Joint Projects

Levels	Federal	Regional	State	Local
Federal	BEH/OCS Project ——— NIMH/DDO/BEH Adv. Project	Regional Training Conferences	Regional MR Center construction	BEH First Chance Project ——— TADS
Regional	De-instit. Demonstration Project ——— PCMR Conference	Region IV OHD with Region VIII OHD ——— Region VIII/IX client track	DDTI Region IV	Regional HEW DD Office with state residential faculty and state institutions
State	DD Council formula grant ——— DDTAS	Region IV OHD with North Carolina agencies, programs and universities	Tennessee/ Arkansas joint planning ——— Interstate compact on residential care	DD Council Projects
Local	BEH University Training Grants	Regional OCD with Head Start locals	Rehabilitation Sheltered Workshops	Consolidated School/Special Education Program ——— Recreation Program

Three critical features of service systems

Effective service programs must (1) include some critical operational characteristics, (2) constitute a comprehensive matrix of service potential, and (3) be continuous or cyclical in nature.

Most service programs are enterprises, not systems. There is not much "systematic" about them. Effective service delivery systems are organized, systematic, evaluatable processes.

1. *Characteristics of service delivery*

There are 4 fundamental characteristics of effective service delivery (see Figure 1).

The *adequacy* of service, as defined by the results or the effectiveness of the availability or application of the service, is the most critical characteristic. Adequacy can only be evaluated in terms of client change as a function of the availability of the service on an active or assertive basis rather than a passive or static basis.

Timeliness of the availability and the delivery of the service is a second critical characteristic. The adequacy of services, that is their availability and easy access, is insufficient unless the availability is there at a time when the handicapped individual is most in need of the service.

The *quality* of service relates to the competence of the persons delivering the service, the relevance of the treatment or remediation to the handicap at the time, and the sufficiency with which the service responds to the presence of the handicapping condition.

The *cost/benefit* aspect of service delivery relates to the extent to which the economic and manpower cost of the development and delivery of the service is justifiable given the prevalence and severity of the condition in the community's view.

The 4 characteristics are overlapping and interrelated. Any service delivery system must include adequate, timely, high quality and cost/beneficial characteristics.

An assessment of service delivery systems along the four characteristics dimensions indicated will yield a general evaluation approach to service delivery systems as well as to provide a conceptual model for use in the development of strategies for providing services to handicapped individuals.

2. *Matrix of services for handicapped individuals*

When attempting to set up or describe a service delivery system, there are several categories or major dimensions along which to construct the program. (See Figure 2, Matrix of Services for Handicapped Individuals.)

The 3 major categories of concern when attempting to capture current or proposed services for handicapped individuals must include (1) the type of service, (2) the client population,

Figure 1

Characteristics of Service Delivery

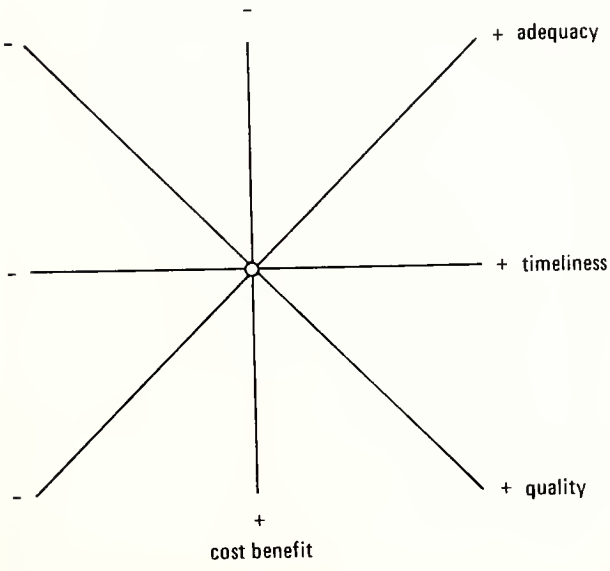
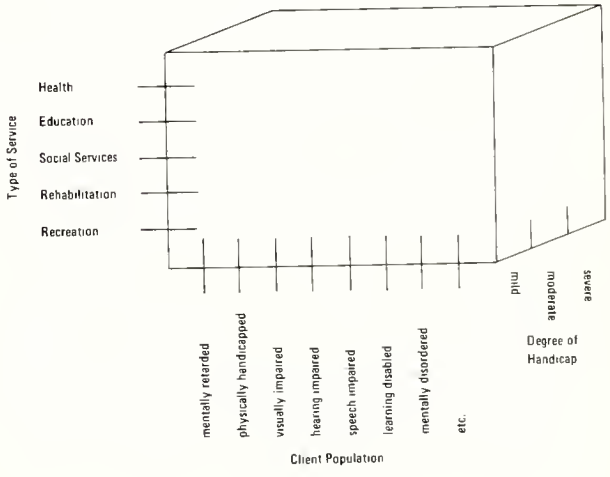


Figure 2

Matrix of Services for Handicapped Individuals



and (3) the degree of handicap. This 3 dimensional matrix provides an opportunity to inspect the full array of service programs that must be present across the developmental or age continuum in order to assure adequate services for handicapped individuals.

The type of service includes health, educational, social service, rehabilitation, recreation and other important service areas.

Client populations include the definable categorical handicaps, including the physically handicapped, the mentally retarded, the mentally handicapped and those with sensory handicaps, such as the visually impaired, the hearing impaired, and the mentally disordered.

The type and intensity of service varies in accordance with the degree of handicap from mild to severe impairment which in turn relates to the prevalance of handicapped individuals in any given community.

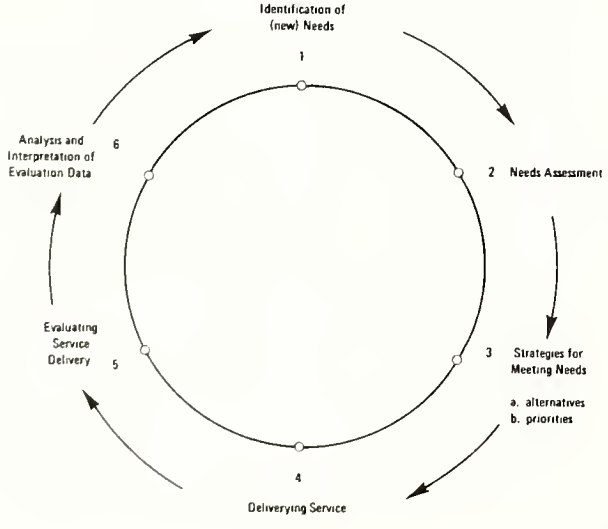
This matrix of services for handicapped individuals is designed to provide a general grouping of the types of services, the types of client and the major dimension of the degree of handicap in order to assess and to plan service delivery systems.

3. *The service cycle*

Service delivery is a cyclical process divided into critical phases of activity (see Figure 3).

Figure 3

The Service Cycle



Any service delivery system must be a dynamic and continuing process of developing and delivering services to handicapped individuals.

There are 6 identifiable phases of the service cycle which must be included in order to have an effective service delivery system.

The *identificatiion of needs* is a prior step to a comprehensive *needs assessment* which can lead to *alternative strategies* for deliverying services or meeting the needs that have been identified and defined.

The *service delivery* phase is subsequently *evaluated* for adequacy, timeliness, quality, and cost effectiveness. These evaluation data are then *compared* with the possible consequent reduction of the earlier identified needs or the *identification of new needs* for comprehensive assessment, the development of alternative service strategies and a continuation of the cylce.

PROBLEMS AND RECOMMENDATIONS

A review of current issues and a perusal of current service delivery systems reveals some factors which need to be addressed begining immediately and over the next few years.

1. The Integration of Human Service Systems:

There has been an ever expanding rhetoric on this topic over the last few years. General statements of problems and goals constitute the bulk of the statements coming from all levels, both public and private. Essentially, the discussions and presentations on the "integration of services" and the need for an improved method of integration and coordination amount to a body of general belief or prevailing philosophy that is commonly held by professionals and the special interest groups which comprise the constituencies of this effort, especially in the area of handicapped individuals. In a report by Gage (Integration of Human Services Delivery Systems) it is stated that the federal Department of Health, Education and Welfare regards the impact of HEW services as less than the sum of its program parts. This is said to be due to the following—

a. service programs are not *correlated* with a common set of *national* goals and service objectives.

b. they are not responsive to the *multiple* needs of the clients that they serve.

c. they are not *orchestrated* through centralized, comprehensive planning processes of state and local levels.

d. they tend to be *narrowly* prescribed and *rigidly* regulated.

e. they not only fail to complement one another, they typically *do not mesh* with other federal programs inside or outside of HEW.

In addition to the above points, the problem of integrating service programs includes a variety of subfactors.

The political value of remaining unique helps maintain a competitiveness between agencies and specialized service programs that works against the integration of human service programs at all levels.

The difficulty of developing a common or shared information data base slows down the movement toward attempts to develop better integrated service systems.

The development and implementation of services along strictly disciplinary lines tends to hold up cross-agency or inter-agency programming. There is a continued resistence to cross-disciplinary or trans-disciplinary training and manpower development also. Interdisciplinary service and training programs are badly needed.

At the current time there is a slow but steady tread toward integrated human services agencies at the local (county) level which help blend health, mental health, rehabilitation, social services and other programs rather than maintain the current, separate generic agencies.

At the top (the federal level), there is an attempt to blend together health, education and welfare or social services programs within the Department of Health, Education and Welfare. This situation might well be inverted to the point where a separate, cabinet level, federal agency would be established for health, for education, and for social services that would provide coordinated planning and the development of criteria, policy, regulations and monitoring activities for an increasingly integrated system of state and local agencies. In other words, the current situation where the local agencies are separate and poorly coordinated and the national agencies are attempting to come into a more blended configuration, should be inverted to separate out federal agencies into special cabinet level programs while the local programs are becoming more blended or integrated. This inversion would allow for a shift away from direct service delivery by federal and state agencies toward a program development, resource development, technical assistance, monitoring and evaluation role and could place the local (county and municipal) agencies into a more direct, effective, integrated service delivery pattern.

2. **Meshing of Planning, Service, Research and Training:**

The flow of information and activity through the sequence of planning, program development, program implementation, research and development, evaluation, and training is poorly carried out at the present time at all levels. There is a need to orchestrate the planning, resource development, and program development activities of service and training programs, including higher education as well as field-based training and education programs. Further, it is necessary to articulate planning and program development activities with the research, development and dissemination programs which are increasingly remote from the service systems and the training programs designed to staff the service systems.

A regional policy, planning, service, training and program development mechanism should be put in place that would provide for the unique service program responses that arise from the special local state and regional service needs of handicapped individuals. While there is not a great deal of evidence at the present time this regional meshing activity could bring together the necessary information, planning, service, training and research and development programs. It would result in a more effective articulation and delivery of services than is now available.

3. **Improved Match of Consumer-Client Input with Agency-Organizational Input in the Development and Delivery of Service Programs:**

While consumerism has increased at a dramatic rate since the middle 1960s, the Developmental Disabilities Act is the only major piece of federal legislation currently being implemented at the state and local level that requires

consumer involvement and input into the planning, program development and service delivery activity for handicapped individuals.

The involvement of consumers, especially the handicapped, is an absolute necessity to improve the quality, timeliness and propriety of the service needed as well as to guarantee that an appropriate and objective evaluation can be derived in the fact of mounting service program costs.

A Center for the development and study of consumer involvement in human services programs should be established to complement the federal, state and regional organizations now in place.

4. **It Is Necessary To Install A Monitoring, Evaluation and Feedback Activity Into The Planning Process:**

At the moment, information developed for planning, service, training or research programs in the area of the handicapped is not sufficiently accurate or fresh to assure the timely and effective delivery of service. Monitoring the effectiveness of programs, evaluating programs and providing feedback to the planning and program development activity from the monitoring and evaluation activities is poorly accomplished. In addition, there is an urgent need for the development of cost-benefit studies, particularly research into the appropriate measures of input and output of human services programs that would allow for more effective evaluation. Cost-benefit studies, thusfar, have not yielded useful units of measurement or methodological approaches that would result in the program evaluation and cost-benefit statements that are available to industry and agriculture.

A special effort should be mounted to focus the issue of measurement, methodology, and systems for monitoring, evaluating, improving planning and developing cost-benefit strategies for programs in the area of handicapped individuals.

5. **A Review Of The Merits Of Public Education Programs:**

Millions of dollars have been poured into propaganda, public awareness and public education programs in the mental health, special education, rehabilitation, health, and other human services and human development areas. There have been differential effects, mostly measured by success in fund raising. The provision of *knowledge* to the general public about handicapped persons does not necessarily result in improved *understanding* of the nature of handicapping conditions. Neither does it always result in a positive change in the attitudes of the general public toward the handicapped and the positive contributions that the handicapped are making in our society. Further, the mobilization of public interest and public support for service, training and research and development activities in the area of the handicapped has not been as effectively accomplished as is necessary to mount the public support, attention and resources necessary in the years ahead to *prevent* handicapping conditions and to provide for the special service needs of those who are and will be handicapped in our communities.

A special effort must be undertaken to study the variety of strategies which have been used effectively to mobilize public support for other issues. In addition, new approaches to public education and the strengthening of our effort to increase public awareness in the area of the handicapped must be undertaken, particularly among lower socio-economic groups. Without a background of moral and financial support for the variety of programs needed to serve handicapped individuals, no further progress can be made and recent gains will be lost.

6. **Closer Coordination Of Governmental Branches:**

The route of the special interest groups (Notably parents) toward developing service programs for handicapped children and adults has moved from pressures on legislators and congressmen for specific legislation, to pressures on the executive branch of state and federal government for more enlightened leadership, to a legal advocacy which maximizes utilization of the judicial branch on behalf of handicapped individuals (notably class action litigation).

There needs to be a more effective, nonpartisan coordination between legislative, executive and judicial branches with regard to leadership, legislative development, and legal support in order to aid in the development of a more integrated and effective network of human services programs for handicapped individuals.

A mechanism should be established to assist states toward a better orchestration of legislative activity with executive agency implementation which "fits" with the judicial and legal interpretation and enforcement activities within states.

In short, what we may *not* need is further litigation. What we *do* need are successful demonstrations of how current consent decrees can be fulfilled.

7. **The Profision Of Adequate Financial Stability Directly To Handicapped Individuals Is Sorely Needed:**

Social security, insurance benefits (both public and private), stipends, tax relief, job training, job provision and other individual support strategies must be expanded and increased for handicapped persons to the point where the matter of inadequate income does not hamper the handicapped person otherwise coming to grips with the problems of community, family and personal adjustment.

An national program supported by state and local agencies and the general public must be initiated which will provide a guaranteed income through a variety of individual financial supports to handicapped persons so as to assure the personal welfare of each handicapped person in our society.

8. **There Has Been A Lag In The Application of Technology To The Problems Of Handicapped Persons:**

A recent, belated effort on the part of the federal government to transfer some of the technological products developed during the active years of the space program (NASA) constitutes one of the few efforts to systematically review the current and developing technologies (hardware and software) which could be applied to alleviation of those conditions which handicap many of our citizens or to prevent the existence of those conditions which lead to handicap.

The utilization of visual communication technology for diagnostic activities in rural areas, the utilization of new types of materials for prosthetic devices for physically handicapped, the use of computer-based instructional system for the mentally disabled and other activities are but a few of the many opportunities that may lie in a systematic review of the full spectrum of technological development experienced in this country over the last 30 years which might be of some immediate and long term value for handicapped persons.

Similarly, those special inventions developed for handicapped persons (deaf, blind, mentally disabled) might be of great benefit to other special populations in our country and around the world.

9. **There Has Been A Continued Focus On Defect Rather Than On Evnironmental Determinants And The Arrangement Of The Environment To Prevent Or To Alleviate The Effect Of Handicapping Condition:**

The continued notion that a *handicap* is a defect results in persons being labeled and seen as *deviant* in the general society. This works against the best interests of the handicapped person and retards or perhaps precludes advances in the adequate understanding of handicapping conditions and the development of adequate service delivery systems to meet the needs of handicapped individuals.

Greater support should be given to developing and expanding the base of knowledge which has grown over the last few years which takes an ecological approach to the understanding and alleviation of the effect of handicapping conditions, especially mental disability. Environmental and socio-cultural determinants of handicap are poorly understood. Improved research, development and demonstration service programs need to be mounted in order to more full explore this major source of handicapping conditions and handicapped persons and the extent to which environmental manipulation and cultural redefinition might provide satisfactory remedial and preventive measures.

10. **The Role Of Higher Education:**

Higher education, particularly graduate schools and community colleges, are still inadequately involved in the training effort required to develop and implement a comprehensive and effective service delivery system for handicapped

individuals throughout the country at the local level.

The traditional role of higher education as the source of knowledge generation must change significantly in the direction of a needs-related training strategy which includes joint planning with service programs. In this way, the data base necessary to plan and develop service programs can be shared between the manpower development organizations and the service delivery systems with a consequent orchestration and synchronization between the two systems. The current situation where service programs are being planned and developed only to be stalled by the lack of adequate numbers and types of personnel is unnecessary and unforgiveable given the state of the art of our current planning and evaluation skills.

Higher education is, in most instances, available and willing to participate in the development of objectives, priorities and strategies for meeting the service needs of handicapped individuals. However, an extra effort must be made to help link the institutions of higher education with the service delivery systems, especially at the state level, in order to assure adequate joint planning and program development and the successful delivery of competent staff, on time, for the necessary service programs. This will require special block funding to universities for correlated work with service agencies.

11. Continuing, Back-up Support Systems For Services:

Insufficient attention has been paid to the need for continuing technical assistance organizations, to provide for in-service training, staff development, consultation, resource development and the program assistance necessary, on a continuing, back-up support system basis, for service programs. Demonstration programs, information dissemination, skill development, capacity building and technical assistance are a necessary part of any comprehensive service delivery system. Dissemination is an expensive process but one which is necessary if research products are to reach practitioners.

Technical assistance is a process whereby new knowledge, materials, special skills and information about related service activities can be brought to even the smallest element of a comprehensive service network in a systematic way. Technical assistance organizations, typically limited to small state and regional agency staffs, must be expanded to provide the kind of continuing support and assistance necessary to help mount a significant local service delivery effort.

12. There Is An Inadequate Relationship Between Public Education Agencies And Human Resources Agencies At The State Level:

Over the past several years nearly two dozen states have created "umbrella agencies" which have brought together mental health, health, rehabilitation, social services and other human services agencies under a common bureaucratic format. In no instance is public education included in these umbrella agencies. The net effect can be to make one of the largest enterprises of value to the handicapped individual more remote from health and other human resources programs. It is important in each state to develop and maintain an adequate planning, coordination and evaluation linkage between education and other human service programs at the state level. The situation may be particularly acute in states where state education agency heads are *elected* and the other state agency officials are *appointed*. Often–times this situation results in differing political backgrounds and constituencies which can work *against* effective inter-agency program planning and program development, especially between human resources and education. This type of partisan and unnecessarily differentiated agency activity should be circumvented where possible.

Cross-cutting programs such as an Office for Children, a Department of Administration, a legislative analysis unit, or others can be initiated in order to soften the effect of the remoteness often found between education and other state agencies around the country.

13. Education Represents The Greatest Investment Of Resources:

Despite the fact that education represents the greatest investment of resources and perhaps is of the greatest developmental benefit for the handicapped, documentation and research from the field have been relatively sparse when

compared with other areas of service affecting the handicapped, e.g., vocational rehabilitation. However, because recent litigation and legislation are highlighting the educational needs of the handicapped, it is likely that the quantity and quality of documentation in this field will dramatically increase. This, along with a national commitment to provide full educational opportunities for all handicapped children by 1980, demands more information than currently exists. Consequently, the need for educational research, development and dissemination (now at an all-time low ebb) is greater than ever. Personnel and funds for field-based research on practical educational problems should be developed at the federal and state level. A minimum of 15% of the service delivery system budget for education should be earmarked for research, development and evaluation.

14. **Lack of Services To Eligible Persons:**

There are currently numerous federal and state programs, designed to serve the handicapped, that are not full enrolled. In some cases, only about 50% of those eligible for the programs are being served. Such programs as Supplementary Security Income (SSI), Early Periodic Screening, Diagnosis and Treatment (EPSDT), and Vocational Rehabilitation programs for the severly handicapped are significantly under-utilized. This is primarily due to a lack of public awareness and agressive outreach by these programs. It is also due to the fact that the programs are not currently prepared for full enrollments in terms of finances, manpower, and organization.

Service providers must be reorganized and prepared to enroll service eligibles. Services need to be promoted through public awareness campaigns. To cut costs, the red tape of screening must be reduced.

When new services are developed, they should be tied as closely as possible to generic services and combined with the outreach, screening, and registration of other services directed toward the same populations.

The high cost of services, limited enrollments, service gaps, and lack of outreach is due to the fact that many services addressed to the handicapped are administered out of separate agencies. For example, services such as screening, food supplements, day care, early education, parent counseling, and health care for handicapped infants and toddlers are often provided by social services, public health, education, mental health and even some private agencies. While each of these agencies may have an important role to play in the delivery of services, the duplication of administrative costs and the gaps and duplications of services must be reduced.

Counties and other local districts must develop single "ports of entry" where *all* service entry points converge and administrative costs are shared. This would help assure cooperation and coordination of service providers, increased public awareness, and reduce the need to search for services.

Single agencies should become responsible for the administrative costs, supervision, and coordination of services for different age levels. For example, public health—from pregnancy to age five, public schools—from age five to sixteen, vocational education and rehabilitation—from age sixteen to twenty-one, social services—from age twenty-one and up, etc.

15. **Expensive Service Delivery Models:**

Many of the models of service delivery for the handicapped were developed with limited intentions and under unique service situations. Because of this, many of the service models now in use have become extremely expensive, e.g., institutional care and self-contained educational classrooms. Less expensive models to deliver better quality services must be utilized, e.g., handicapped children removed from self-contained classrooms to regular classrooms with resource support.

The long-run cost-benefit of service models must be determined and projected so that models employed will be cost beneficial in the future, financially and socially. For example, developing 50 to 100 bed facilities to replace large institutions may be cost effective now, but over the long run may produce the same high costs of our current outmoded institutions.

The long term benefits—both in terms of client progress and costs—of smaller, more "normal" residential facilities the high costs of our current outmoded institutions should be assessed prior to the allocation of capital resources into larger institutional programs. Solutions closer to the mainstream of life are less

likely to continue to require special costs over the long run, e.g., special transportation.

16. Lack Of Adequately Trained Personnel:

Services for the handicapped, more than ever before, require personnel who are, at the same time, both generalists and specialists. Service delivery personnel need to know their specialty. They also need *transdisciplinary training* (how to use other disciplines) in order to respond to the handicapped on a variety of dimensions and to know *when* to access other specialists. Current personnel do not often provide the full range of services needed. Too often, they use expensive, specialized services when not needed. Personnel planning services face the same dilemma—their specialized knowledge actually limits their usefulness. Manpower trained in a variety of human services areas (public health, education and social service planning) are needed to adequately plan the coordination of comprehensive services rather than to continue the current uncoordinated, categorical and specialized services.

In-service training in transdisciplinary decision-making for key service personnel and human service systems for planners is desperately needed. Regional pre-service, in-service, and technical assistance systems are needed to provide such continuing education for key service personnel.

17. High Overhead Costs Of Federal And State Programs:

Federal and state program costs have shown a demonstrative and significant increase in the last few decades. This is largely due to the confusion and mixing of planning, decision-making, administering, monitoring, evaluation, reporting, and service delivery costs.

The federal and state agencies should *contract* for services delivered, thus retaining only the planning and monitoring costs and cutting the overhead costs of direct service delivery.

Federal and state government should provide block grants to private and public agencies closer to the service level. These grants should be provided with carefully defined standards of service but with limited specifications of methods of service to be used. Federal and state governments should get out of the business of providing direct services.

18. Lack Of Continuity And Continuing Responsibility

Because of the segmented nature of the current delivery system, many handicapped individuals whose problems are multi-faceted and of a long-term nature are forced through a rat's maze of overlapping and discontinuous programs. Many are often tost "between the cracks" and are underserved. The result in several instances is social isolation and regression. This problem is particularly visible among mentally disabled persons released from institutions. Because there has been non one agency accountable for followup and service planning, many of these individuals are exploited and abused in inadequate community facilities.

Though it has been recommended that integration of services is necessary to resolve the problem, in the interim there is a critical need for a a system of case management capable of providing continuing attention to the needs of the handicapped and assisting such persons in securing the variety of service and financial entitlements which are their rights as citizens.

NEW DIRECTIONS

It should be evident from this paper that the major need today is orchestration, consolidation, integration and the improvement of the quality and effectiveness of the activities we now have. We are in the midst of a "great American dream freeze." Therefore, a major emphasis on bold new thrusts and directions is not here recommended.

There are a few innovative, new directions suggestions that should be offered and considered:

1. There is a need for expanding and *decentralizing our policy development* and *program evaluation processes.* The development and implementation of policies and procedures related to the implementation of effective services for the handicapped has been for too long centralized and isolated from the main body of the service enterprise. Regional and local policy development activities need to be mounted in

order to improve the quality and quantity of direct services to handicapped individuals.

2. We still work largely without a *comprehensive data base of information* necessary for effective planning, resource development, client tracking systems and monitoring procedures. Without the rapid development of a comprehensive and shared information and data base, no national network of services can be effectively developed or evaluated.

3. The clear need for *continuing support of service program activities* begs for the establishment of regional and local technical assistance, evaluation, staff training and management programs. Unless the service machine is continuously oiled and adjusted, it will soon become obsolete and sputter to a non-productive halt. Technical assistance organizations, both public and private, should be continued and expanded with the major focus directed toward the development and maintenance of effective service programs.

4. The need for integration of services and the coordination of planning and program activities has been recited before. However, *new models of coordination, collaboration,* and *integration of services* should be developed from a basic and applied research effort. Funds should be made available to engage organizational research and development activities to improve our attempts to maintain effective, coordinated and integrated service systems.

5. We have yet to fully mount a comprehensive *preventive services program* which would include health, economic, mental health, educational and social services. The fundamental and long range answers to the problem of handicapping conditions is to prevent their occurance in the first place. Comprehensive research, development, training and demonstration services need to be developed in the area of prevention.

6. A program of case management is definitely needed to assist handicapped persons to "negotiate" the disparate service system and to provide a continuing relationship with such persons during the course of their disability. At present, there is no one accountable agent responsible for maintaining ongoing contact with the handicapped person. Without this direct accountability, handicapped persons will continue to be underserved and "lost" in the system.

7. Finally, a continuing and escalated effort must be maintained in the area of *advocacy on behalf of handicapped individuals* and the modification of public attitudes toward the handicapped and their place in our society. The deviancy model is still too widely held. Evaluation is still conducted toward exclusion rather than inclusion. The focus on employability and a productive slot in the corporate state still overshadows the equally, or perhaps more, important goal of improving human development and the quality of life for the handicapped person.

REFERENCES

AFL-CIO policies and programs in the field of rehabilitation. Unpublished mimeo, July 1972.

American Federalism: Toward a more effective partnership. A report from the National Conference of American Federalism in Action, Washington, D.C., February 20, 1975.

Barry, Patricia. *Summary of the comprehensive needs study.* The Urban Institute, Washington, D.C. September, 1975.

Boggs, Elizabeth, Federal legislation affecting the mentally retarded, 1955-1967. *Mental Retardation*, Volume III, Grune and Stratton, New York, 1971.

Boggs, Elizabeth. Federal legislation affecting the mentally retarded, 1966-71, *Mental Retardation*, Volume IV, Grune and Stration, New York, 1972.

Chadwin, M. L. The nature of legislative program evaluation. *Evaluation,* Volume II, February, 1975.

Conley, R. *The Economics of Mental Retardation*. John Hoplins Press, Baltimore, 1973.

Gage, Robert W. Integration of Human Services Delivery Systems, *Public Welfare*, Winter, 1976.

Long-range projections of the service needs of handicapped individuals. Office for Handicapped Individuals, DHEW, Washington, D.C., March, 1975.

Long-range projection for the provision of comprehensive services to handicapped individuals. Report from the Office of Handicapped Individuals, DHEW, Washington, D.C. July, 1975.

Smedley, L. The role of organized labor in the rehabilitation of the handicapped. Paper before the World Congress of the International Rehabilitation Medicine Association, Mexico City, October, 1974.

Stedman, D. The state planning and advisory council on developmental disabilities, *Mental Retardation*, Volume 13, No. 3, June, 1975.

SERVICE DELIVERY SYSTEMS FOR HANDICAPPED INDIVIDUALS

Prepared by

Charles W. Hoehne
of the
Texas Commission for the Blind

Edited by

Paul Hoffman, Ph.D.
University of Wisconsin—Stout
Menomonie, Wisconsin

CONTENTS

	Page
Introduction	373
The Right to Services	373
The Reality of Services	374
The Inherent Inappropriateness of Utilizing Omnibus Agencies as Service Delivery Mechanisms for the Handicapped	376
The Rehabilitation System As a Model—Its Strengths and Limitations	381
A Basis for an Improved Service Delivery System for the Handicapped: Modifications and Refinements to the Rehabilitation Model	386
Selected Bibliography	392

PREFACE

A national conference conducted for the purpose of improving the condition of handicapped Americans cannot ignore certain overriding realities which characterize the existing service system.

The first and hardest of these realities is that the existing service system simply does not effectually touch the lives of anything approximating a majority of those handicapped individuals who need, want, and could benefit from the adequate and timely provision of specialized services.

A second reality is that the existing service system is, when regarded in broad dimension, actually a loose and poorly coordinated constellation of assorted programs and facilities—a fragmented array of special programs conducted by a diversity of organizations, each having generally narrow and limited objectives for the services it offers. For the purposes of this paper, the term "existing service system" encompasses both public and private effort; the term includes rehabilitation services, special education, social services, income maintenance programs, special housing and transportation activities conducted in behalf of handicapped individuals, health services, advocacy efforts, affirmative action programs, effort to abate both the obvious and the subtle barriers confronting handicapped individuals, and anything else conducted for the purported purpose of assisting individuals with handicapping conditions.

A third reality is that organizations serving the handicapped are currently operating in an era in which ever-increasing expectations must somehow be balanced against critically finite resources.

The fourth reality, which should be the operative one insofar as those participating in the White House Conference on Handicapped Individuals are concerned, is that most of the effort exerted on service delivery systems in recent years to address the three basic problems noted above has failed.

The national service system for handicapped individuals is an aggregation of smaller service systems. Some of these operate on a national basis, others are statewide in scope, and the operation of still others is restricted to particular locales. The mission of certain of these smaller service systems is to serve handicapped individuals only; other service systems attempt to serve handicapped individuals as an incidental part of providing services to much larger populations. For reasons which will be more fully identified in this paper, the costs of services to handicapped individuals are generally higher and the impact of such services less when the responsibility for serving the handicapped is placed with a system also responsible for responding to the needs of a broader population.

The concept of "human services integration" is currently fashionable among those who would initiate and direct that process of change through which service delivery systems for the handicapped are reorganized, dismantled and ultimately assimilated into larger programs concerned primarily with serving larger populations than the handicapped. Also in vogue among this circle is the formulation of conceptual models for advancing the principle of "human services integration." What is unfortunately lacking among this group is the inclination to evaluate honestly, pragmatically, and in relation to traditional service delivery systems the effectiveness of the new service delivery systems they design, advocate and, if fortunate on a short-term basis, ultimately operate.

The need for change and improvement in service delivery systems for the handicapped is not denied; the existence of that need is freely stipulated. What is challenged is the inadequately examined assumption that actual improvement in service delivery systems has anywhere resulted by diverting public attention to the drama and illusion of change.

Beneficial change and meaningful improvement in service delivery systems for the handicapped undoubtedly can and should be achieved through diverse approaches to service delivery. Beneficial change and meaningful improvements in services to handicapped individuals, however, are not likely to be accomplished through the mindless replication of poorly considered conceptual models which, where implemented, will upon careful scrutiny and objective evaluation inevitably stand exposed as inadequate and ineffective mechanisms for serving people with handicapping conditions. It is submitted that more constructive results can be achieved for everyone concerned by an effort to minimize the admitted deficiencies, imperfections and limitations of certain existing models for service delivery.

Handicapped Americans are entitled to adequate, effective and timely services. Those who contribute to the payment of the costs of those services are entitled to optimum efficiency and acceptable levels of cost-effectiveness. The objective of promoting excellence in services to handicapped individuals is not in

conflict with the objective of promoting cost-effectiveness in service delivery systems; instead, the two objectives are fundamentally compatible, inherently consistent, and mutually interdependent.

But for these objectives to be advanced, certain essential preconditions must exist, a particular service climate must be maintained, and the basic prerequisites for programmatic effectiveness must be preserved.

THE RIGHT TO SERVICES

The basis upon which services to handicapped individuals is predicated is central to issues concerning service delivery systems.

No longer is the provision of adequate and appropriate services to handicapped Americans to be regarded as a matter of charity, compassion, or even simple conscience. Instead, those services are today to be regarded as a matter of equity, enlightenment, justice and basic individual right.

Two centuries have passed since our system of government was established. In founding this Nation, men banded together pursuant to what some have referred to as a "social contract" theory. In large part, that theory holds that in order to advance the common good of all, individuals living within the regime of our particular system of government subordinate a certain part of what would otherwise be the inherent freedom and inalienable rights of every individual.

A complex industrialized, technically oriented, urbanized society has evolved under this system of government. America is today an interwoven array of intricate but pervasive economic, cultural, legalistic, social and other institutions. Its architecture, systems of transportation, communications media, processes of production and marketing, patterns of family living, recreational outlets, and opportunities for personal growth and development are all essentially designed to accommodate the circumstances and predilections of the great majority of its citizens.

America today is a society in which handicapping conditions are produced as part of the price paid for benefits which result generally to the advantage of the majority. It is a society in which the capacity of medical science to preserve and prolong life by far exceeds the capacity of the social sciences to make life meaningful and worthwhile for those who are society's casualties or the victims of genetic aberrations.

Today's American society is not something that grew and developed with any significant thought being given to the special needs and unique problems of handicapped citizens. Although a sizable minority in their total number, the handicapped as a group have tended to be too hidden and silent a minority to promote adequate attention to equity and right in any of the public arenas which impinge upon their daily lives.

And as a result, handicapped individuals must today live in a world that evolved with inadequate attention being given to the question of how to design environments and institutions to accommodate not only the great majority but also the minority of the blind, the crippled, the deaf, the infirm, and the mentally handicapped. It is a world in which, absent adequate specialized services, basic personal survival is placed at issue; it is also a world in which, given the current level and quality of the specialized services purportedly available, the value of personal survival is called into question by many handicapped individuals.

Whatever application social contract theories of government might have had to handicapped individuals in the 18th Century, though, the right of the handicapped to appropriate services can no longer be regarded as a legal principle waiting to be established. This right has been established as a result of both the progressive evolution of the law and the basic direction in which contemporary society has developed. It is being defined with increased precision by legislative bodies, and by the courts who perceive the existence of that right as a Constitutional guarantee existing independent of legislation.

However the right to service standing alone does nothing to improve the daily life of a handicapped person. It is only when the handicapped individual has access to a relevant and responsive service delivery system that the right to services takes substantive meaning.

Successful access to a relevant and responsive service delivery system denotes considerably more than what many handicapped individuals receive from some of the major service delivery systems. More is required of service delivery systems than token gestures, however sympathetically made. More is required than the mere provision of simple survival skills or assurances of the basic subsistence with which to meet minimal living needs.

A handicapped individual's right to services is only meaningful when the service delivery system has the inclination and capability to provide services with genuine concern, with reasonable promptness, and with significant impact. The impact of services must be substantial enough not only to contribute to the support of life, but also to promote a level of quality and meaningfulness in the handicapped individual's life. The service capability should be sufficient to afford handicapped individuals a range of options to strive for in achieving the least restrictive lifestyles of which they are capable.

The fundamental professional responsibility of any service delivery system for the handicapped is not confined to accomplishing the narrow and limited goals defined for the service delivery system; the purpose of all services ultimately should be to assist handicapped individuals in achieving their goals and objectives. This does not require that a service delivery system for the handicapped ignore or subordinate its defined goals and objectives, but it does imply the existence of a basic professional responsibility to interface adequately and effectively with related programs provided through other human service delivery systems. The performance of a service delivery system cannot be relevantly evaluated simply by looking at the number of handicapped individuals successfully placed in gainful employment, the number of special education students awarded degrees, the number of cash assistance checks written, or any other such tangible measures.

A new, larger and more pertinent approach is needed for assessing the performance of service delivery systems. That approach must be one which tends to shed greater light on this fundamental evaluative inquiry: What does this service delivery system specifically do for its handicapped clientele and how does it interact with everything else impinging upon handicapped individuals, so as to assist its handicapped clientele to become more adequate, effective, independent and productive human beings? This inquiry represents the essence of what the "right to services" means when related to handicapped individuals.

THE REALITY OF SERVICES

The current problems confronting handicapped individuals undoubtedly would be less serious if only the handicapped had been served with a degree of intensity and thoroughness comparable to that with which they have been studied during the past two decades.

From the early Sixties to the current times a number of studies and activities highlighting the need for services and programs for the handicapped have taken place. In the early Sixties comprehensive studies and planning efforts were undertaken in most states in behalf of the retarded. Following the 1965 amendment to the Vocational Rehabilitation Act each State became involved in statewide planning for Comprehensive Vocational Rehabilitation services to the handicapped. Since then information has been gathered on the deaf-blind, deaf and hard of hearing, developmentally disabled, and on persons with handicapping conditions resulting from heart attack, strokes, cancer, aging and learning disabilities.

As a result of these efforts a number of common factors have been determined. First, and of extreme importance, was the fact that the disabled population studied are generally considerably larger than have been estimated. Second, existing service delivery systems generally were not geared to be responsive to unique problems of the disabled groups studied. It became consistently evident new approaches were needed for specific disabled groups. Finally, it was determined that equitable and economically sound reallocations of available resources were needed to meet the needs of these specific populations.

The salient fact is that there has been study after study in state after state, and nowhere has it been found that anything approximating a majority of the handicapped individuals eligible for services is in fact being served with reasonable effectiveness. The basic conclusions almost universally reached in these prior studies of handicapped citizens are at this time overwhelmingly being verified by state activities currently being carried out and concluded in conjunction with the 1977 White House Conference on Handicapped Individuals.

Disappointing though this verification process may be, if lasting benefits are to be derived from the White House Conference on Handicapped Individuals, it seems prudent to examine those positive gains achieved through prior study and planning efforts, to identify those factors and conditions present in most areas where services to the handicapped have improved over the years, and to relate those factors and conditions to current trends in human services.

One practical and virtually universal result of prior studies of disabled populations has been that additional money has been thrown at the problems and situations identified in these studies. In certain instances, the additional money (especially when accompanied by improved utilization of previously established levels of funding) has led to discernible improvements in services; in other instances, services have not improved measurably and may have even tended to deteriorate further.

Where prior studies and planning efforts have successfully laid a predicate for improvements in services for handicapped individuals, the follow-

ing factors and conditions usually have represented part of the follow-up on the study and planning effort:

1) Ambiguity, indefiniteness or conflict in the basic charge or mission given to a particular service delivery system has been eliminated or reduced;

2) The service delivery system has then been encouraged and enabled to direct virtually all of its time and effort toward the business of carrying out its defined charge or mission;

3) Responsibility and accountability for performance has been clearly affixed throughout the service delivery system;

4) Realistic increments have been made in the level of resources available to the service delivery system;

5) The service delivery system has arranged, either formally or informally, for consideration of the views of recipients of services in matters bearing upon policy formulation and execution, as well as the perceptions of recipients of services in an effort to evaluate the effectiveness of the services provided;

6) Reasonably adequate methods have been developed by the service delivery system for testing and applying the most advanced technology, scientific achievement, and psychological and social knowledge to solve the human problems to which the service delivery system is expected to respond;

7) The method by which the service delivery system has been operated has been such as actively to foster and encourage greater specialization and even subspecialization on the part of individuals working within the system;

8) Authority for formulating, interpreting and modifying policies and procedures has been reasonably related to management responsibilities for carrying out policies in conformity with procedures;

9) Those responsible for the provision of services to eligible individuals have been infected with a sense of mission that is not obscure, confused or compromised; and

10) Circumstances and available information have allowed operational planning to be carried out and acted upon with reasonable soundness.

These ten factors and conditions have most frequently been developed in those service delivery systems whose mission is not diluted by expectations of addressing human problems other than those of handicapped individuals. These factors and conditions, moreover, become most pronounced in separate agencies for the blind and in other service delivery systems primarily organized to serve particular disability groups: the deaf-blind, the retarded, quadriplegics, etc.

Rarely, however, do these factors and conditions come into existence to any significant extent where a service delivery system's responsibility for addressing the needs of handicapped individuals is blurred, diluted and detracted from by a responsibility for also serving a larger population than the handicapped. And where factors and conditions of the foregoing type have not come to be substantial characteristics of the service delivery system, meaningful improvements in services generally have failed to materialize or services in certain instances have even deteriorated—notwithstanding the amount of additional funding provided to the service delivery system.

In certain areas of the country, ombudsmanship and client advocacy programs have been established for handicapped individuals. Reportedly, the bulk of the complaints currently being received from handicapped individuals do not relate to services extended through specialized agencies solely and exclusively concerned with assisting the handicapped, but instead to problems arising when the service delivery system for the handicapped is a part of a system also responsible for serving a larger population.

A judicially or legislatively articulated right to services on the part of handicapped individuals is meaningful only to the extent that viable services are actually provided on an effective basis by a responsible service delivery system. Where the handicapped are a minority within the total group a particular service system is responsible for serving, the practical experiences of handicapped individuals in attempting to get prompt and meaningful services through that type of a service delivery system are such as to present serious questions about the effectiveness of a generalized approach to service delivery.

In contrast to the Broad Service delivery systems the state-federal program of vocational rehabilitation is a service delivery system concerned solely with assisting handicapped individuals. This focus has enabled the development of a particular methodology, distinct areas of professional specialization, and a broad assortment of specialized facilities and resources for ameliorating the handicapping consequences of various disabling conditions. The level of specialized resources and expertise embodied within the delivery system is such that the state-federal

program of vocational rehabilitation is, even with its admitted limitations and deficiencies, unquestionably the most effective system currently available to handicapped individuals. Its effectiveness is such that it is primarily to the state-federal program of vocational rehabilitation that most handicapped adults look or are referred for services. In contrast to the levels of support provided other systems serving the handicapped, the federal appropriation for the basic support of vocational rehabilitation services throughout the nation currently is only $740 million.

THE INHERENT INAPPROPRIATENESS OF UTILIZING OMNIBUS AGENCIES AS SERVICE DELIVERY MECHANISMS FOR THE HANDICAPPED

Theoretically and abstractly, a service delivery system *might* serve handicapped individuals effectively regardless of how or where that system is organizationally located. When actual service outcomes are empirically and pragmatically evaluated, however, it becomes abundantly plain that there is a clear relationship between the effectiveness of a service delivery system for the handicapped and the kind of organizational setting in which the service delivery system operates.

Increasingly, handicapped individuals are expected to look to large "umbrella agencies" for services. It has been fashionable in certain places to consolidate numerous human services programs into such omnibus agencies, and the trend in recent years has been in that direction. At this time, however, there is growing evidence that dissatisfaction with the practical results of this approach to human services may soon result in a reversal of the trend; particularly is this true insofar as programs for handicapped individuals are concerned.

Where the responsibility for operating a service delivery system for the handicapped is placed within a large umbrella agency, the professed advantages and benefits of such an arrangement accrue neither to handicapped individuals nor to the general public that underwrites the costs of services to the handicapped. It was noted by the Council of State Governments (COSG) in a 1974 publication entitled *Human Services Integration,*

> "There is no evidence that reorganization of human services saves money in absolute terms and there is substantial evidence that successful merger and integration requires additional dollars in the implementation phase . . ." [pp 63–65].

In the same report, the Council notes the usual rationale offered in behalf of going to the umbrella model of a service delivery system:

> The need for integrating the delivery of human service programs is typically illustrated by the needs of a hypothetical family: it lives in dilapidated housing; the mother is in poor health and functionally illiterate, and the father has a prison record, so jobs are difficult to obtain and hold; one son is picked up for theft and is thought to be on drugs; another appears retarded; and a daughter is pregnant. The needs of such a family can only be met through a variety of services—financial assistance, counselling on various problems, health diagnosis and care, education and training, and correctional programs. These services are rendered by a number of governmental agencies, each with its own system of entry, diagnosis, referral, treatment, reporting and follow-up. Similar services may be offered by separate agencies, while other services may not be available in the locality . . . . The concept of human service integration is addressed to overcoming these problems and meeting the needs of people.[4]

Whatever the merit of this rationale as applied to most human services programs, it has obvious deficiencies when related to services for handicapped individuals. For one thing, most handicapped individuals probably would be inclined to regard the hypothetical family described in the above explanation as being somewhat atypical.

For another thing, this hypothetical family unit illustrates, microcosmically, the fundamental fallacy and inherent ineffectuality of the "human services integration" when applied to handicapped individuals. The fact that no severely handicapped individual is included in the above hypothetical family unit may inferentially reflect the amount of consideration proponents of "human services integration" give to the actual needs of severely handicapped individuals and to the practical functional requirements for meeting those needs effectively. If a severely handicapped individual—for example, a deaf-blind teenager—is added to this family unit and the sequence of the service delivery process under an integrated human services approach is carefully thought through in terms of probable outcomes for the family in general and in terms of the probable

impact of services upon the deaf-blind teenager in particular, the need for specialized service delivery systems for the handicapped becomes distinctively illustrated.

The deaf-blind teenager in this hypothesis will, for the generalist who is primarily responsible for attempting to address the total needs of the family, represent an exceptional problem. Part of the problem will be that a field worker who is trying to be all things to all people will have to develop information about the availability of approaches and resources for meeting the needs of a deaf-blind individual. Other aspects of the problem will be that services for the entire family unit will aggregate into a substantial investment of public funds, and that proper services for the severely handicapped teenager will necessarily be more costly and lengthy than for other members of the family. The individual working with this family, therefore, will have a problem in trying to show quick returns through nominal investments of funds.

As a practical matter, it is quite probable that under a human services integration approach to the hypothetical situation, the needs of the deaf-blind teenager would be ignored or responded to inadequately. This is overwhelmingly the experience of severely handicapped individuals whenever they are forced to seek services through a service delivery system charged with the responsibility of assisting a large population of individuals with assorted problems, most of which are less complex than the problems associated with severely handicapping conditions.

Another serious but inadequately examined flaw in the hypothetical case advanced in behalf of the proposition that integrated human services are necessary is the apparent assumption that public resources are so infinite that services can effectively be provided to solve all human problems. One wonders if elected public officials might have been less willing to get aboard the human services integration bandwagon if anyone had looked at the hypothetical family referred to in the COSG report and then taken the additional step of totaling the cost of governmental effort to try to resolve all of the human problems identified in that example.

The reality is that public resources are finite—and becoming increasingly more finite. There is a limitation on the amount of tax load the general public can carry without an entire set of additional socio-economic problems being established. There is, similarly, a limitation on how much of the gross national product can effectively be directed toward the resolution of problems of particular groups without occasioning new problems or acerbating existing problems for other groups.

Given the reality that government currently does not have the capability to try to solve each of the human problems of each of its citizens, it would seem necessary to establish a system of priorities in the field of human services. The attitudes, judgments, and values of our society, moreover, are such that one would presume that this system of priorities would be established with considerations about the equity and economic soundness of services to particular groups representing the primary criteria relied upon in making the various determinations necessary to the process of establishing priorities. One would further assume that, as a simple matter of equity and demonstrated economic soundness, the process of establishing priorities in which those with the most severe problems would be served first. Under that kind of system of priorities, it would be expected that handicapped individuals would tend to receive priority in a manner commensurate to the severity of their handicapping conditions.

In actual operation, however, a service delivery system based upon the integrated human services concept invariably has the practical effect of producing a superciliously inverted set of priorities. Whether by design or as an inevitable function of the daily dynamics of the system, those with the less serious problems tend to get served first and people with catastrophically disabling conditions either get ignored or served inappropriately. The integrated human services concept is sold in the name of efficiency, the right kinds of numbers and statistics are required to demonstrate efficiency, and favorable statistics—if not favorable service impacts and outcomes—are produced by giving at least informal priority to people with the less serious problems. This, then, is one of the more obnoxious things about omnibus agencies in the field of human services: the needs of the services system itself are not compatible with the individual needs of the people who should have a superior claim on the resources available to the service delivery system.

Returning to the hypothetical family unit referred to in the above excerpt from the COSG report, when a service delivery system is predicated on human services integration, there are powerful and compelling pressures built into the

service delivery system which tend to make the system most responsive to the people who need services the least. A family living in dilapidated housing does, to be sure, have a problem. So, too, does a functionally illiterate mother with poor health, a juvenile delinquent who is experimenting with narcotics, a pregnant daughter who is unwed, and an unemployed father with a prison record. But problems of this type, however unfortunate, are hardly so exceptional and limiting as to place personal survival in jeopardy in the absence of special services.

There are those who would argue that socioeconomic problems of this type are largely self-induced and, to a substantial extent, self-perpetuating. This line of reasoning leads naturally to the contention that this particular species of human problems should become subordinate when the process of establishing priorities in the field of human services is being conducted. It is not the purpose of this paper to examine, extend upon or rebut a proposition containing those kinds of value judgments and moral connotations. Instead, the purpose of this paper's analysis of the general failure of omnibus agencies to respond effectively to the needs of handicapped individuals is to focus consideration on the reasons why service limitations are inherent from a functional standpoint.

In addition to the reasons already identified as contributing to the ineffectiveness of omnibus agencies in providing services to the handicapped, there are also other functional factors. For one thing, proponents of human services integration simplistically theorize that all human problems are essentially the same because, in the final analysis, people are always involved. This fallacious proposition then becomes the guiding principle for the entire service delivery system, thereby assuring that the service delivery system will be grievously flawed from the very outset.

Human problems are not that simple and uniform in nature. Human problems do not have the sameness many planners have assumed. Each person burdened by factors which impinge upon him and limit him in his capacity to function successfully and to compete effectively in our society is unique. The factors which impinge upon the individual can be extraordinarily complex, not infrequently so subtle as not even to be recognized by the individual himself at the outset, and always exceptional as to the individual involved.

For many, adverse socioeconomic circumstances are, in and of themselves, problems to be dealt with and hopefully overcome. For most handicapped individuals, though, adverse socioeconomic circumstances are merely complicating symptoms attending the more serious problem of a physical or mental disability. The indicated prescriptive treatment for dealing with one kind of problem may amount to nothing more than a placebo when used to treat an entirely different set of human problems and may even, in fact, be harmful. Is it not understandable, though, that there should be a tendency on the part of the omnibus agency employee who is confronted with the problem of trying to provide services to people with diverse sets of human problems to "give the same medicine to everyone"?

In the perception of increasing numbers of enlightened professionals, services to the handicapped are most likely to be effective if handicapped individuals themselves have meaningful expression and appropriate influence in the process through which determinations are made about the nature and scope of the services they are to receive. Herein is contained another reason why the human services integration model can be devastating to the interests of handicapped individuals. The usual approach, as the Council of State Governments noted in its Human Services Integration report, is to place with the head of the comprehensive human resource agency overall authority in the areas of personnel, planning, policy-making, budgeting and resource allocation, administrative rule-making, regulations, and evaluation.

In relation to services for the handicapped, this approach means that every essential element for an effective program is removed from those who are actually responsible for carrying out the program and placed with an individual who is not solely and exclusively concerned with the matter of assisting handicapped individuals. Typically, the head of the comprehensive human resource agency must respond to a broad range of controversial problems and needs in order to survive professionally. The more controversial problems and needs do not generally involve handicapped individuals, but usually relate to the larger population the organization is responsible for serving.

From the perspective of handicapped individuals, a major problem with the comprehensive human resources agency is that basic decisions which vitally affect the lives of the handicapped are made by individuals who tend to have little knowledge of, involvement with, or interest in

services for the handicapped. Accountability becomes blurred in that kind of organizational framework, because endless possibilities for bureaucratic buck-passing are created. Administrators responsible for the effective delivery of services to the handicapped become ensnarled and fettered with red tape. Organizations of handicapped individuals find themselves working with and talking to people who do not have the authority to make final decisions. Proposals for improvements in services must be submitted through numerous layers of bureaucracy. There are interminable delays in the decision-making process. Infighting between different offices and divisions of the comprehensive human resources agency becomes rampant as staff jockey to advance their personal positions instead of concentrating on the business of advancing the interests of the agency's clientele. Basic policy decisions are influenced by all kinds of extraneous considerations which have little if anything to do with requisite factors for strengthening and improving services for the handicapped. Procedures for resolving grievances about services tend to become so elaborate and time-consuming that it is virtually impossible for a handicapped individual to pursue those procedures effectively. Administrators with little practical knowledge of the basic functional requirements for operating an effective service delivery system for the handicapped initiate superficial and simplistic economy moves which set the stage for programmatic complications that result in an enormous waste of available human and fiscal resources.

Freezes on hiring and restrictions on travel are typical examples of this. In an office with several blind professionals, there is no economy in refusing to hire a secretary, but this happens frequently when administrative decisions and personnel operations are made and conducted at levels far removed from daily work situations. Similarly, it is fundamentally absurd for administrators to have to take annual leave and go at their own expense to conferences dealing with the basic rules applicable to programs involving millions of dollars in resources, but this is not at all uncommon.

And those who are both a part of the service delivery system and astute soon perceive that career advancement is best facilitated by serving the needs of the organization rather than the needs of the people for whom the service delivery system is supposed to exist in the first instance.

That bigger, more rigid, and more inflexible bureaucratic structures do not represent the way to serve handicapped individuals effectively was the major conclusion of an extended management study completed in 1975. The study was one in which Management Services Associates (MSA), a firm extensively involved in the planning and evaluation of governmental programs in the field of human services, examined the effectiveness of state services for the blind under the various organizational arrangements currently existing for the delivery of those services. Financed without governmental support, the MSA study is thought to represent the only extensive and objective investigation to date made of the capacity of comprehensive human resources agencies actually to realize the purported benefits and advantages of such service delivery systems.

While the MSA study was primarily directed toward services for the blind, the basic findings and conclusions are applicable to services for all disability groups.

Basic flaws in the reasoning process which leads to proposals for comprehensive human services agencies are identified in an MSA report entitled *An Evaluation of the Organization of State Programs To Serve the Blind* [4].

The report notes that governmental organizations tend to follow functional lines based on the premise that the same type of skills can be utilized in management and program delivery. While the work in tangible areas such as material procurements, it does not work adequately in the more non-tangible areas such as human service. The report states that those who would combine human service agencies disregard the fact that there can be success in those agencies that have critical differences among their operations. This is true, only if the personal client relationships are preserved and the intensity of the relationships maintained. The report claims that the failure of welfare programs to meet the needs is due to the failure to resolve the problems that create the needs.

If the above is true, the MSA report asks, why then does the trend continue towards the development of umbrella type agencies. The answer is in the acceptance of two basic assumptions which the report labels as myth. The first is the assumption that "like-sounding" functions will lend to more efficiency, economy, and client services. As was pointed out this works in tangible areas, such as material procurement, but not in the human service area with its myrid of

problems and specialized needs. The second assumption that proves to be a myth in human service is that of "economy of scale". The report notes that business has found that bigness does not always lead to success, especially in people-oriented businesses. The report goes on to state that functions of government relating to problems of people do not lend themselves to the economy-of-scale concept either.

Factors accounting for the tendency to amalgamate programs for the handicapped into comprehensive human services agencies were identified in the MSA report as including the following:

> In the late 1960's both the federal government and state governments came under increasing criticism because most of the costly welfare-type programs showed poor results in client return to self sufficiency. Also, cost projections showed staggering growth in the years ahead. The only part of this complex spectrum of governmental service that showed any degree of success in client return to productivity was the rehabilitation programs. This was achieved despite small budgets and limited numbers of staff (although the staff quality tended to be exceptionally high when compared to other governmental human service programs). Rehabilitation became the "major" term to be used to cover many programs that lacked the necessary low client-worker ratio which was reinforced by high caliber staff. In addition, the rehabilitation programs were rapidly increased in size of scope of operation as well as numbers of cases being handled. In too many instances too rapid growth diluted the quality of intensive service that originally led to success. As more programs were introduced these two major problems combined to produce something less than the success that most Congressmen and Legislators thought would happen overnight. [4, pp 8–9]

The MSA report then concludes that the trend toward attempting to serve the handicapped through the establishment of comprehensive human service agencies has had a generally negative impact upon the effectiveness of services:

> While the federal bureaucracy was being changed to try to achieve more effective programming and thus reduce public criticism (and the attempts to do so are still continuing) the changes taking place in state government organization were even more sweeping . . . .

State reorganization did not precisely track the federal government pattern. With a longer tradition of "reform and fad" movements, state government was confronted with criticisms on a wider range of issues. For example, the need for constitutional modernization, better control over state government expenditures, economy in government, more effective use of tax dollars and reduction in number of state agencies, all became key political issues in many states.

As an attempt to respond to these functional areas of criticism a trend has been set in motion to consolidate state agencies based on the "economy of scale" concept. In some states it has taken the form of a massive combination of all (or nearly all) human resource agencies. This is often referred to as an "umbrella" agency approach. In other states fewer "human resource" functions were combined in one agency. Differences in approach, operational strategy, clients being served, specialized training of staff for effective client services—all these vital considerations were pushed aside. As one "Human Resource" agency head said, "We should be able to develop one field force to serve all types of social problems. All you need is someone with a degree in sociology or a related field with a few weeks' training." Indeed! Obviously this person had not studied the complexities of the steps in the rehabilitation process.

During all of these attempts at agency consolidation, whether on a massive scale with many agencies involved or on a mini-scale with only a few agencies involved, the same tired phrases were repeated, "It will lead to more efficient use of the tax dollar; it should reduce expenditures; it is a more businesslike approach," etc. Rarely, if ever, the impact of such reorganization on clients and their needs was mentioned. [4, pp 10–11]

The MSA report is recommended as a basic document for anyone seriously interested in improving services delivery systems for the handicapped.

In a statement of organizational policies and principles adopted by the National Council of State Agencies for the Blind in the late Sixties, the NCSAB asserted that,

> The answer to complex human problems does not lie in the establishment of cumbersome, multi-layered bureaucratic organizations. To the contrary, relevant and responsible public

programs are best developed by reducing to the maximum extent possible the distance between the level of client needs and the level of policy formulation and executive decision-making . . . .

A 1970 article in the *Journal of Rehabilitation* speaks to the matter of appropriate focus and adequate accountability in services delivery systems. Tracing the impact of legislation which in 1943 allowed separate state agencies for the blind to receive federal rehabilitation funds, the article contains a comment which should be carefully considered by handicapped persons who are attempting to ascertain why they are dissatisfied with services received through comprehensive human resources agencies:

> Some indication of what the 1943 amendments meant to the blind of this country may be gleaned from the following comparison: in 1936, general rehabilitation agencies reported that they had successfully rehabilitated two blind persons; in federal fiscal year 1969, 8,884 visually disabled persons were reported successfully rehabilitated by state agencies for the blind; and the figure for federal fiscal year 1970 is projected at approximately 10,500.

A devastating analysis of the results of a generalized approach to the provision of services (as opposed to a specialized approach to services) is set out in a paper presented to the National Citizens Advisory Committee on Vocational Rehabilitation in the mid-Sixties. In that paper, the proposition is stated thusly:

> There is no special mystery about services to or rehabilitation of the blind. There are, however, special problems and special difficulties encountered in services to this disability category. Efficient and effective services for the visually disabled can best be accomplished with specialized techniques, specialized skills, and specialized resources.

Unfortunately, the fostering and efficient use of specialization, whether to meet the special problems of the blind or of any other disability category, is antithetical to the primary conceptual premise of the comprehensive human resources agency. That is why the specialization required for effectiveness in services to the handicapped is eroded rather than enhanced when primary responsibility for the delivery of those services is placed with the comprehensive human resources agency.

It is not argued that services cannot be improved and delivered more efficiently at this time by fundamental structural changes in the service delivery system for handicapped individuals. The indicated changes in the service delivery system, however, do not consist of the currently fashionable tendency to rely upon the comprehensive human resources agency as the service delivery mechanism for handicapped individuals.

In some communities and states, refinements and improvements to existing service delivery systems are needed. In other communities and states, entirely new service delivery systems critically need to be developed.

THE REHABILITATION SYSTEM AS A MODEL—ITS STRENGTHS AND LIMITATIONS

The proposition that has been argued to this point has been that, by the great weight and preponderance of available evidence, effective services to the handicapped are at best a gross improbability when the service delivery system consists of a comprehensive human resources agency.

In point of fact, following consolidation into comprehensive human resources agencies, a number of state rehabilitation programs have managed to continue to provide services to the handicapped at reasonably adequate levels of effectiveness, albeit at somewhat greater cost and with a perceptible deterioration in quality. Where reasonable levels of effectiveness are maintained by state rehabilitation programs, however, this is most generally attributable to factors which are functionally unrelated to the functional requisites for an effective service delivery system. The administrator of the state rehabilitation program has good leadership qualities, the head of the comprehensive human resources agency is happy to delegate virtually complete authority for a complex program involved with a population that is troublesome to serve, the state rehabilitation program has strong political support, consumer organizations are well organized and provide the program with external leverage, etc.—any combination of these factors may exist and primarily attribute for the continuation of a reasonably effective rehabilitation program following consolidation of that program into an umbrella agency.

It is unfortunate that personal and political factors of this type can change quite rapidly.

Many instances can be cited in which rehabilitation services in fact deteriorated rapidly following such changes as turnover among key personnel, the loss of public office by one who has been an effective program advocate and supporter, internecine conflict among consumer organizations, or the erosion of other factors which had made it possible for the state rehabilitation program to be more a part of an umbrella agency on paper than in fact.

Recognizing this and frankly facing the reality that a majority of state rehabilitation programs are currently situated in the kinds of organizational structures that present a clear and present danger that future changes and developments might provide impetus for those programs to become less responsive to the needs of handicapped individuals, the Council of State Administrators of Vocational Rehabilitation (CSAVR) undertook in 1975 to identify the essential characteristics of an effective rehabilitation service delivery system. In a position paper authored primarily by Sandra Wess of the Texas Commission for the Blind and adopted by the CSAVR at its 1976 Spring meeting, that organization committed itself to the advancement of policies and legislation to assure that every state rehabilitation program—regardless of where located in the state government—would effectively possess what the CSAVR regarded as the minimal requisites for delivering services to the handicapped with a reasonable level of effectiveness, including the following:

> (1) Vocational objective of the program as the primary focus;
>
> (2) An individualized approach to evaluate all handicapped and to serve eligible handicapped people;
>
> (3) Responsibility for advocacy and opportunities for the handicapped;
>
> (4) A full-time vocational rehabilitation administrator, and trained specialized staff devoting themselves to the vocational rehabilitation program with clear lines of supervisory and administrative authority;
>
> (5) Built-in accountability;
>
> (6) Direct access to legislative and budgetary and executive processes; and
>
> (7) Preservation of the integrity of the vocational rehabilitation program through the direct responsibility for funds, staff, and client eligibility. [1, pp 2]

The perceptions and basic positions set out in that policy statement are commended for serious study by anyone genuinely interested in developing improved service delivery systems for the handicapped. While this document is narrowly directed to the state-federal program of vocational rehabilitation, the document nonetheless embodies a number of basic principles and concepts which would appear, with minor modification, to be fully and profitably transferable to other programs for the handicapped.

The rehabilitation service delivery system is suggested as the model for a larger service delivery system for the handicapped for a number of reasons. Not the least of these reasons is the fact that the rehabilitation service delivery system accomplishes defined goals and objectives—both of the system and of the handicapped individuals served by the system—better and more efficiently than any other service delivery system for the handicapped.

Apart from a general record of effectiveness, the rehabilitation service delivery system has other strengths and attributes which commend that system as a model to be emulated in any effort to devise total service delivery systems for the nation's total handicapped population:

1) The rehabilitation service delivery system represents precisely that blending of governmental and private philanthropic effort required if the total needs of the nation's handicapped citizens are to be addressed in an effective, non-duplicative, and non-wasteful manner;

2) Built into the rehabilitation service delivery system is the flexibility to adapt to the diverse conditions encountered in different communities;

3) The greatest body of experience in working with the handicapped is found in the rehabilitation service delivery system, as is the greatest part of that cadre of professional workers skilled in working with the handicapped and the larger part of the specialized resources required for serving various disability categories effectively;

4) The state-federal program of vocational rehabilitation has for years been mandated to enter into cooperative arrangements with and to utilize the services and facilities of state agencies administering public assistance programs and other programs for disabled individuals such as the developmental disabilities programs, veterans' programs, health and mental health programs, educational programs, workmen's compensation programs, manpower programs, and public em-

ployment offices. There has been a similar mandate for entering into cooperative arrangements with the Social Security Administration, the Office of Workmen's Compensation of the Department of Labor, the Veterans Administration, and other federal, state and local public agencies providing services related to the rehabilitation of handicapped individuals.

5) The basic methodology of the rehabilitation service delivery system—comprehensive diagnosis and evaluation of all factors which impinge upon a handicapped individual and limit him in his ability to function independently and productively, specific service planning to achieve defined and measurable service outcomes, the tailoring of services on the basis of individual circumstances, and the provision of specialized services by staff who have been specifically trained to assist the handicapped—is a basic methodology fully utilizable in any kind of service effort exerted in behalf of handicapped individuals;

6) Although flexible enough to be adaptive to the varying conditions which obtain in different states, regions and cities, the rehabilitation service delivery system nevertheless has a degree of uniformity everywhere in the nation sufficient to assure a basically fair and equitable type and level of services to most handicapped individuals, regardless of where they might live; and

7) The rehabilitation service delivery system is already in place, with representation in every significant center of population throughout the country and could accordingly become, with a high degree of efficiency and minimal delays, the nucleus or basic undergirding of a broader national service delivery system for handicapped individuals.

An eighth attribute of the rehabilitation service delivery system deserves separate discussion. That attribute is the rehabilitation system's inclination for introspection and self-criticism. The system, particularly the part of it that consists of the state-federal program, is constantly examining itself, reviewing its processes, assessing its outcomes, and striving for an improved definition of its basic mission. The system is at once its own best critic and its own best catalyst for improvement. Internally, the system is chronically dissatisfied with itself.

This quality of internal dissatisfaction with the status quo becomes increasingly more useful and, if constructively exploited, could serve as the springboard for establishing an improved system of service delivery for all handicapped individuals.

There is, in fact, a substantial basis for both providers and recipients of services to be dissatisfied with the rehabilitation service delivery system. Given the problems of the people it is supposed to serve and considering the progressively less tenable restrictions on the level of resources allocated to the state-federal program of vocational rehabilitation, the rehabilitation service delivery system unquestionably accomplishes more with what it has to work than do most human resources systems.

Even so, the rehabilitation service delivery system currently has great potential for becoming more beneficial to more handicapped individuals. The system has a long way to go if its performance is to become commensurate with the increasing expectations of handicapped individuals. Too many handicapped individuals, particularly the most severely disabled, are either untouched by the rehabilitation system or, at best, served inadequately.

One needs only to read the testimony received at recent hearings on rehabilitation legislation to recognize that the handicapped are expecting more of the rehabilitation system, that there is growing bitterness about the practice of excluding from the benefits of services available through the system those handicapped individuals for whom employment is not thought to be feasible, that the rehabilitation system needs to define its basic mission more comprehensively, and that the system needs to interact more effectively with the primary service delivery systems for children and the aged in order that handicapped individuals at either end of the spectrum can be reached and served better.

The thrust of much of the testimony offered by handicapped individuals at Congressional hearings on the federal Rehabilitation Act has been reaffirmed at the state conferences of the White House Conference on Handicapped Individuals. The testimony received at these state conferences shows that handicapped individuals are indeed interested in jobs, but that they need more than employment. Across the nation, the handicapped have been saying that they want and need a service delivery system which not only enables them to become more productive in an economic sense but also, on a more fundamental level, tends to enhance the quality of their daily lives.

This is evident from a review of the issues addressed at both regional and state meetings. Emphasis has been placed upon improved infor-

mational services to promote greater public understanding and acceptance of the handicapped as individuals. The need for improved advocacy services for the handicapped has been stressed at virtually every meeting. Issues such as transportation problems, architectural barriers, and special housing requirements have been emphasized extensively. The desirability and essential soundness of extending services to allow a greater degree of independent living on the part of handicapped children, elderly handicapped individuals, catastrophically disabled persons and others for whom employment is not practicable or feasible have been overwhelmingly demonstrated at these regional and state meetings.

But can the rehabilitation service delivery system adapt itself so as to be responsive to these kinds of concerns, problems, and unmet human needs? Realistically, this question can only be responded to affirmatively if the system has the basic internal inclination to make those adaptations required in order to enable the system to be more relevant to the total population of handicapped individuals.

That internal inclination does exist and it is becoming more perceptible throughout the entire system. Had H.R. 8395 become public law, it would have contributed greatly to a reduction of many of the kinds of problems handicapped individuals have been deploring during these past months at regional and state meetings throughout the United States.

H.R. 8395 was vetoed on October 27, 1972. The practical effect of that veto was to delay an impetus toward improvement and greater relevance which had evolved from within the rehabilitation system itself.

In a policy statement entitled "The State-Federal Vocational Rehabilitation Program Looks to the Future—A Statement of Mission and Goals" adopted by the Council of State Administrators of Vocational Rehabilitation in the mid-Sixties, the CSAVR conceptualized the role of the rehabilitation system in the following manner:

> 1. Vocational rehabilitation services provided by state rehabilitation agencies as their sole responsibility under the [federal Rehabilitation Act] and related legislation.
> 2. Vocational rehabilitation services provided by state rehabilitation agencies in cooperation with other agencies which have related legal responsibilities for serving various groups of handicapped people.
> 3. Services provided by state vocational rehabilitation agencies which may not be vocational rehabilitation services as defined in the [federal Rehabilitation Act]. [2, pp 9]

In elaborating upon this concept, the CSAVR position statement says this about the core program of the rehabilitation system:

> The first circle represents the core mission of the vocational rehabilitation agencies, which is to provide vocational rehabilitation services as defined in the [federal Rehabilitation Act] to all handicapped youth and adults who may apply or are referred to these agencies for such services, so far as their resources will permit. This caseload will consist of those handicapped individuals, the responsibility for whose rehabilitation is not shared in any substantial way by any other agency operating with state or federal funds. This does not mean, of course, that state vocational rehabilitation agencies will not utilize the services of other agencies in serving these applicants for vocational rehabilitation. The point here is that the rehabilitation of such clients is the basic unshared responsibility of the state vocational rehabilitation agency. At any given time, there are hundreds of thousands of such people, and they include handicapped persons in many categories of disability. [2, pp 10]

An affirmative obligation to interact effectively with other programs serving handicapped individuals was recognized in the position statement. That responsibility was explained in the following terms:

> The second circle represents responsibilities of state vocational rehabilitation agencies for the rehabilitation of certain classes of handicapped people for whom some other agency or agencies have a related responsibility. For instance, a department of mental health may have responsibility for some aspects of the care of the mentally ill . . . . The legal responsibility of the vocational rehabilitation agencies to provide vocational rehabilitation services to these groups of people is no less than for the groups of handicapped people for whom no other agency accepts responsibility. Rehabilitation services cannot be provided, however, in isolation; such services, to be most effective, must be coordinated with the services of the

other agencies that have related responsibilities. This means that the vocational rehabilitation agency and the related agency must develop cooperative arrangements that assure an uninterrupted continuum of services resulting in the rehabilitation of the individuals involved. Since the sole concern of the vocational rehabilitation agencies is to the vocational rehabilitation of the disabled, and the related agencies have concerns which may have priority over vocational rehabilitation, it is the responsibility of the vocational rehabilitation agency to initiate the development of cooperative programs which will result in the vocational rehabilitation for those eligible for these services. [2, pp 10.]

The final area of the rehabilitation system's responsibilities was conceptualized in the following language:

> The third circle represents secondary responsibilities which numerous state vocational rehabilitation agencies have been asked to assume under state and federal laws, the objectives of which are related to and not in conflict with the [federal Rehabilitation Act] and state vocational rehabilitation legislation. For instance, a state vocational rehabilitation agency may be chosen to provide rehabilitation evaluation and referral services for the clients of other agencies as well as for its own clients; or a state vocational rehabilitation agency may contract with a public welfare agency to provide vocational rehabilitation services to welfare clients who need such services, without regard to the eligibility of such individuals for vocational rehabilitation services; or a state rehabilitation agency may operate a school for the blind or deaf, a talking book program, or a sight conservation program . . . . [S]tate vocational rehabilitation agencies now contract with the Social Security Administration to make determinations of disabilities under the disability benefits program. [2, pp 11–12]

To the extent that parts of the foregoing language can be read as inviting an ill-advised excursion into services for individuals who do not have physical or mental handicaps, this part of the CSAVR policy position is no longer operative. In certain programs, services to the severely handicapped were somewhat diluted during the late Sixties when rehabilitation agencies attempted to expand services to disadvantaged individuals whose primary problems were more psychosocial than in the nature of medically identifiable physical or mental disabilities. The federal Rehabilitation Act of 1973, among other things, shifted the focus of program effort back toward people who were truly handicapped, to the extent that the state-federal program was mandated to establish and observe priorities favoring the more severely handicapped individuals. The position statement adopted by the CSAVR in 1976 clearly commits the state-federal program of rehabilitation to the provision of services to handicapped individuals without diminishing that effort by also trying to provide services to individuals who are not handicapped within the usual meaning of that term.

The 1976 policy statement also goes much further in addressing a functional requirement which has been of considerable concern at every proceeding conducted in connection with the White House Conference on Handicapped Individuals: advocacy and the fostering of better opportunities for the handicapped. The most recent policy statement sets out this perception of the advocacy and opportunity role of state rehabilitation agencies:

> State vocational rehabilitation agencies were legislated into existence many years ago specifically to provide the services needed by handicapped people to achieve economic independence. In assisting handicapped individuals to achieve their vocational goals, a successful rehabilitation program must grapple with the social stigma that is attached to a handicapping condition. In other words, handicapped individuals are disabled to the degree that they are unable or are *not permitted* to function to their fullest potential. In this context, state rehabilitation agencies have developed specialized and sophisticated programs focused upon the social acceptance and adjustment of handicapped individuals within our society, while promoting and encouraging society to meet its responsibility and to allow suitable opportunities for the handicapped to realize their vocational potential and to function as fully participating members of society.
>
> The advocacy and opportunity role of state rehabilitation agencies has long been recognized by the Council of State Administrators of Vocational Rehabilitation. The agencies have accepted responsibility for:
>
> (1) Developing and implementing programs directed toward public understanding of the nature of handicapping conditions and the

number of people affected, the difference between a handicap and a disability, the kinds of services needed for rehabilitation, and the benefits to individuals and to society derived from rehabilitation programs;

(2) Helping to create an accepting environment for handicapped people in the community and to remove or lower barriers to the full participation of handicapped people in community life; and

(3) Working with other public agencies with related responsibilities to assure that handicapped people for whom the various agencies share responsibility coordinate their efforts to achieve a continuum of services directed toward meeting the total needs of handicapped people.

Given this role of advocacy, it is imperative that responsibility be held by the state administrators of vocational rehabilitation with undivided loyalties and obligations, and that they be provided access to the resources necessary to meet that responsibility. [1, pp 4–5]

On the other hand, the most recent position statement may fall a bit short in terms of addressing one of the other primary unmet needs which handicapped individuals are identifying through the current White House Conference activities: the need to provide services which enable severely handicapped individuals to live more independently when circumstances are such that employment goals are not practicable or feasible. The 1976 position statement touches upon this in part in the following language:

> . . . [I]t is recognized that some individuals may never be able to achieve a vocational goal in the traditional sense, but it is difficult indeed to accurately predict which individuals are not capable of success. Rehabilitation professionals know of successful handicapped individuals whose potential for success was not recognized initially by others. Since all of us are handicapped to some extent by the unawareness of our latent potential, and since we are culturally conditioned to grossly exaggerate the limitations of mentally and/or physically handicapped individuals, it is not unexpected that many handicapped people see themselves as very limited or even useless. It is essential, therefore, that services be provided on an individualized, personally tailored basis, utilizing the unique expertise and special insights developed within state rehabilitation agencies. [1, pp 4]

The most recent CSAVR position statement does not, however, address the issue of what service delivery system is specifically to provide what types of services to those handicapped individuals for whom vocational goals are not practical or feasible because of such reasons as age, youth, severity of disability, or other factors.

Clearly, it is time for this latter issue to be confronted head-on and to be satisfactorily resolved. The final part of this paper represents one proposal for doing precisely that.

A BASIS FOR AN IMPROVED SERVICE DELIVERY SYSTEM FOR THE HANDICAPPED: MODIFICATIONS AND REFINEMENTS TO THE REHABILITATION MODEL

If the handicapped are defined as including all individuals with physical or mental conditions which, in the absence of appropriate services, limit them in their capacity to function effectively, independently and productively in the kind of world in which they have to live, all of the available data would indicate that this population includes not hundreds of thousands of Americans, but millions.

The size of that population, the uniqueness and complexity of the problems of the people within that population, and the sheer enormity of this population's potential if effectively provided with appropriate services, all dictate that a service delivery system be developed and maintained which functions effectively. It has been suggested in this paper that an extension of the existing rehabilitation service delivery system represents the most viable starting place in the development of a more comprehensive service delivery system for the handicapped. It is now suggested that even with major modifications and refinements to the rehabilitation service delivery system, the new system is not likely to prove useful and effective unless organized and operated in a manner which tends to assure that the effective provision of services to the handicapped represents the sole concern of everyone within the service delivery system.

Minimally, the service delivery system for the handicapped should be plainly characterized—in every state, and in every local community—by the obvious presence of factors similar to what the Council of State Administrators of Vocational

Rehabilitation has identified as representing the seven essential elements of the state-federal program of vocational rehabilitation as that particular program is currently defined.

On a more ideal level, the service delivery system for the handicapped should be separate and apart from all other human resources delivery systems both federally and in every state. Within the federal government, the most effective way to bring about improvements in services for handicapped Americans would be to establish a separate Department for the Handicapped, with a Secretary reporting directly to the President, and with that Department for the Handicapped mandated and empowered to see to it that handicapped individuals actually receive legislatively intended benefits through those federally-supported programs that endeavor generically to serve broad populations of which the handicapped are but a minority.

And as a careful review of the performance records of state rehabilitation programs will clearly show, at the state level the most effective way to bring about improvements in services for handicapped individuals is to set up separate rehabilitation agencies governed by consumer-oriented policy boards that report to governors directly and that relate to state legislatures without any necessity for obtaining clearances from administrators in large bureaucratic structures.

If any useful or fiscally efficient purpose is being served by having the service delivery system for the handicapped ensnarled, entangled and enmeshed with unrelated human resources systems, then that purpose remains to be convincingly suggested, let alone documented and conclusively proven.

But regardless of how government is currently organized and regardless of how it might be reorganized in the future to cure the inefficiencies and ineconomies which have inevitably attended implementation of poorly considered and inadequately examined theories of public administration, a meaningful and effective service delivery system for the handicapped can be established and maintained only if certain basic prerequisites exist:

1) There has to be accountability on the part of the people who work within the service delivery system for the handicapped. The system has to be designed, structured and actually operated in a way which keeps the buck from being passed and the ball from being hidden. If the performance and commitment of people within the system is inadequate, there should be built into that system devices which tend to ensure that inadequacy becomes a rather visible and conspicuous matter rather than something easily hidden or disguised.

2) The people in the organizations making up the service delivery system for the handicapped must be given authority commensurate to their responsibilities. Any organization, regardless of the purposes for which constituted, requires this in order to be effective. The handicapped themselves may have exceptional problems, but there is nothing exceptional about the basic management principles involved.

3) There must be objective, ongoing evaluation of practical service outcomes, as well as effective and formalized planning to remedy identified deficiencies or weaknesses in services.

4) An effective service delivery system for the handicapped can be developed and maintained over a period of time only if the effective provision of services to handicapped individuals represents the only criterion used either formally or informally to measure the performance of people who are a part of the service delivery system.

5) Handicapped individuals who are representative of those for whom the service delivery system exists must have meaningful expression in the formulation of the basic policies under which the system operates, significant participation in the process through which the system's performance is assessed, and substantive involvement in the development and implementation of plans for improving the system.

Although there are variations in the degree to which these basic prerequisites are found in particular rehabilitation agencies, these characteristics as a whole are better exemplified in the rehabilitation service delivery system than in most human resources delivery systems. A primary problem is that because of the way the basic mission of the rehabilitation system is currently defined, these characteristics cannot redound to the advantage of perhaps as much as half of the handicapped population of the country—that half being those handicapped individuals who are too old, too young, too disabled or otherwise in circumstances which contraindicate the immediate goal of employment.

If, then, the rehabilitation model is to be the starting point in developing an effective service delivery system for the handicapped, the first indicated modification of the current rehabilita-

tion system consists of a legal and programmatic broadening of the rehabilitation system's basic mission. That involves, as has been suggested previously in this paper, authority, encouragement and resources with which to provide services which enable those individuals for whom employment is not feasible or practicable to achieve a greater capacity for independent living.

This involves, too, a basic refinement in much of the current philosophical predilection of people working within the rehabilitation service delivery system. No longer should people who are a part of this system rotely conclude that their service effort has failed if a rehabilitation client is not successfully placed in remunerative employment. In the final analysis, after all, whether services have been effective or ineffective represents a matter which cannot appropriately be determined solely from the standards and perceptions of the service delivery system; the client's perceptions of what kind of impact services have had on the quality of his daily life is more relevant to the process of assessing the degree to which the service effort has been effective.

Expansion of the rehabilitation system to encourage the provisions of services for accomplishing independent living objectives should involve, further, the development of improved standards and approaches for measuring the actual outcomes and economic impacts of services provided through this system. It is submitted that the development of a more sophisticated methodology for determining the real impact of services will tend to reflect that in many cases services provided to accomplish independent living objectives will have a greater cost-benefit ratio than do services provided to certain handicapped individuals in which vocational placement is successfully accomplished. Examples of this might be cases in which rehabilitation services result in the deinstitutionalization of a multiply handicapped retardate or cases in which services reduce a severely handicapped individual's personal dependency to the extent that a family member is freed to undertake employment outside the home, in contrast to cases in which only marginal placement is accomplished or in which the handicapped individual leaves his employment within a short period of time following vocational placement. It is suggested that improved measurement of the impact of services can rather readily be accomplished through minor modifications in the individualized written rehabilitation plan and the various statistical and fiscal reporting forms already routinely used in the state-federal rehabilitation program.

Also involved in movement toward services to accomplish independent living objectives, though, is a danger. Because of the basic ethics of our society, because of the social and psychological implications of status as a productive worker, and because of the usual economic implications of employment, meaningful and remunerative jobs represent desired and frequently emotionally essential goals for most individuals. Authority to provide services for the purpose of assisting certain handicapped individuals to acquire the ability to live their personal lives with a higher degree of independence, therefore, implicitly has this practical danger for both severely handicapped individuals and for the rehabilitation service delivery system itself: Services should never be provided for the more limited purpose of advancing independent living objectives if an intensification of effort and a higher degree of aspiration on the part of both the handicapped individual and the service system might even remotely be expected to result in the formulation and achievement of vocational goals. One possible approach toward the minimization of this possibility of handicapped individuals and their service delivery system not aiming high enough and not striving for the maximum attainable is found in the rehabilitation legislation vetoed by former President Nixon in 1972.

Another modification or refinement which the current rehabilitation service delivery system would seem to require in order more effectively to respond to needs and concerns expressed in the various proceedings conducted incidental to the White House Conference on Handicapped Individuals is an expanded enumeration of the system's specific responsibilities (in addition to assumption of general responsibility for the independent living services discussed above). In its earlier "Statement of Mission and Goals," the Council of State Administrators of Vocational Rehabilitation defined the basic responsibilities of the state-federal program of rehabilitation thusly:

> (1) *The administration and supervision of a program of vocational rehabilitation services directly to the nation's physically and mentally handicapped youth and adults* . . . . Rehabilitation services include the provision, whenever appropriate, of any or all of the following services: diagnosis, physical restoration, counseling, training and related services, placement

and related services, and any . . . services . . . that are appropriate for the determination of the rehabilitation potential of a handicapped individual over an extended period of time. This program of direct services is the heart of the responsibility of the state vocational rehabilitation agencies.

(2) *Development of a state-wide plan for the provision of comprehensive, high-quality vocational rehabilitation services to all who need them.* This includes the development of a state plan for an adequate network of rehabilitation facilities and workshops to serve handicapped people. Although the general state-wide planning effort is a state responsibility, rather than a vocational rehabilitation agency responsibility, the agency has been given prime responsibility for leadership in such studies in most states.

(3) *Working with other public and voluntary agencies and local communities to establish, staff, and operate workshops and rehabilitation facilities.* A related responsibility is to act on applications of local communities for federal funds to support rehabilitation facility projects.

(4) *Providing consultative services to workshops in the development of workshop improvement and technical service projects* and recommending the approval of such projects to the Secretary of Health, Education and Welfare.

(5) *Developing contracts with and providing consultative services to workshops and rehabilitation facilities engaged in training programs* supported by federal training grants and allowances to individuals.

(6) *Conducting research and demonstration activities and providing consultative services to community organizations developing research and demonstration projects and expansion programs.* A related responsibility is acting on applications for federal financial support for such projects when they involve services directly to handicapped people.

(7) *Making certifications to the Wage and Hour Division of the United States Department of Labor of individuals who are not capable of open employment but are capable of some production* and making certification to the Department of individuals that are undergoing evaluation and training programs in workshops.

(8) *Working with the United States Department of Labor and the United States Employment Service in the provision of diagnostic services and assistive devices to assure success of training of individuals* under the Manpower Development and Training Program.

(9) *Developing and carrying out programs directed toward public understanding* of the numbers and classes of handicapped people, their problems, the kinds of services needed to assist in their rehabilitation, and the benefits to the handicapped individuals and to society resulting from such rehabilitation.

(10) *Helping to create an accepting environment for handicapped people in the community* and to remove or lower barriers to the full participation of handicapped people in community life.

(11) *Working with other public agencies with related responsibilities* to assure that handicapped people for whom the various agencies share responsibility coordinate their efforts to achieve a continuum of services directed toward meeting the total needs of handicapped people. The rehabilitation agencies should initiate such cooperative programs and, where appropriate, accept responsibility for coordinating the services of the agencies involved in providing the services. This includes the authority to work with local units of government.

(12) *Developing and conducting innovation programs,* identifying and testing new and improved methods of providing rehabilitation services to handicapped people.

(13) *Administering the Randolph-Sheppard Act* under which business opportunities are made available to blind people in federally administered buildings.

(14) *Working with the Social Security Administration in making determinations of eligibility* of applicants for OASDI benefits and in providing vocational rehabilitation services to beneficiaries of the Trust Fund. [2, pp 4–6]

In its 1976 policy statement, the CSAVR has recognized another responsibility as having been added to the fourteen enumerated in the earlier document. The additional responsibility, of course, was the advocacy and opportunity role of state rehabilitation agencies, as discussed in the preceding part of this paper.

Should the state-federal program of rehabilitation take on the responsibility of independent living services, then this, together with the other fifteen identified responsibilities of state rehabilitation agencies, could represent the core component of the overall service delivery system for the

handicapped. The total service delivery system for the handicapped, however, needs to include more than a reasonably adequate mechanism for carrying out these specific service responsibilities. In virtually every state, the various meetings conducted in connection with the White House Conference on Handicapped Individuals have demonstrated that the handicapped regard certain additional elements as being critical to the effectiveness of their total service delivery system. These additional elements include, but are not restricted to, the following:

1) More adequate information and referral services. It has been noted that people with disabilities frequently find themselves additionally handicapped by an inability to get information about available services, resources, special equipment and devices, etc. Even when a handicapped individual has general knowledge about what is available, it is not uncommon for him to encounter difficulty in trying to find out where to go to obtain what he needs, what the cost will be, etc. Suggestions for reducing this problem have included such things as computerized listings of special resources, telephone numbers, and mailing addresses; the establishment of incoming WATS lines which handicapped individuals could use for information; expansion of programs of radio reading services for the blind and reading handicapped; acceleration of projects to design improved communications media for the deaf; and more frequent mailings of general information to interested members of particular disability groups.

2) Mechanisms to assure positive referral to organizations providing generalized services and meaningful follow-up to encourage the initiation and effective provision of appropriate services subsequent to referral. Handicapped individuals are frequently referred for services through educational, social services, health, and related resources which endeavor to serve populations of which the handicapped comprise only one group. Those referrals do not always result in the timely extension of appropriate services. Generally, this failure of appropriate services to be provided on a timely basis is simply a function of staff at the generic resource not understanding the special problems associated with different types of handicapping conditions, not having the knowledge to serve the handicapped individual effectively, and not knowing how to exert effort to acquire the understanding and information necessary for the prompt initiation of appropriate services. It has been frequently suggested in connection with the White House Conference activities that the specific assignment of responsibility for following up to determine what happens after these referrals are made would, if placed with mechanisms containing an adequate amount of expertise and a primary commitment to the interests of handicapped individuals, tend to assure greater accountability, more appropriate services, and more efficient utilization of existing resources.

3) Ombudsmanship and individual client assistance. It has been noted that the rights of handicapped individuals are frequently observed in the breach. Examples include such things as lapses in the enforcement of affirmative action requirements, violations of statutory prohibitions against discrimination in hiring or in access to public facilities, the failure of State Merit Systems to accommodate the handicapped adequately in relation to testing procedures and other conditions on entry into state employment, etc. As a practical matter, when subjected to these types of indignities, few handicapped individuals have the ability and resources required for seeking relief independently. A considerable need is therefore perceived for having, as a part of the total service delivery system for the handicapped, some sort of external and independent ombudsmanship mechanism for intervention in behalf of the handicapped individual.

4) Greater effort to reduce problems associated with architectural barriers, transportation requirements and housing needs. Although much noble sentiment has been written into various laws dealing with these matters, a specific and appropriate assignment of enforcement responsibilities seems to be generally regarded as the basic precondition to the improved effectualization of legislative intent.

5) Intensification of research and demonstration effort to bring scientific and technological advances to bear more adequately in relation to the special problems of handicapped individuals. The possibilities are apparently endless: computerized Braille, condensed speech, telesensory systems, CATV services for particular disability groups, and improved utilization of space age technology are simply a few of the examples which have been cited. At this time, the basic problem with trying to bring scientific and technological advances to bear more adequately upon the unique needs of the handicapped is twofold: (1) many developments, while perhaps well-intended, are grossly oversold and actually have only a minute part of their purported benefits for

handicapped individuals and (2) most of these developments, especially initially, are so expensive as to be beyond the reach of most handicapped persons. That is why it has been frequently suggested that the specific assignment of responsibility for coordinating, tracking and testing research and demonstration effort in this area would be advisable and efficient.

6) Improved cultural, social and recreational opportunities for the handicapped. This is fairly self-explanatory. It implies such things as library systems becoming more attentive to the needs of the handicapped, greater awareness of handicapping conditions and how to accommodate those conditions on the part of persons associated with public parks and programs of public recreation, and an expansion of volunteer effort. This, however, is something that cannot effectively be promoted by any one handicapped individual or even by a particular group of handicapped individuals. That is why a need for the specific assignment of responsibility for stimulating improvements in these areas has been widely perceived.

It is not suggested that, from a systems point of view, it is essential for the rehabilitation service delivery system to take on these additional responsibilities. On the other hand, it is suggested that, as a practical matter, it is rather critical that the rehabilitation service delivery system have substantial involvement with whoever does assume the responsibility for these functions, if the responsibilities are to be adequately discharged.

Certain of the foregoing elements of an effective total service delivery system might most efficiently be handled federally and on a national basis. Possible examples of needs which might be most effectively addressed through central national effort include responsibilities for information and referral services or the coordination of greater effort to reduce problems in such areas as architectural barriers, transportation problems, and special housing needs. Other elements might most effectively be established and maintained on a state, regional or local level. Certain elements of an effective total service delivery system for the handicapped may require cooperative and adequately coordinated effort at various levels.

Where currently missing elements of an effective total service delivery system need to be established at the state level or operated within political subdivisions of a state, it may be determined in certain instances to be appropriate and efficient to place those responsibilities with the rehabilitation system. In other instances, it may be determined to be more appropriate and efficient to place certain of these responsibilities, *e.g.*, positive referral and ombudsmanship functions, with other governmental entities, such as a special governor's coordinating office for the handicapped. A diversity of innovative and experimental approaches is particularly needed at the outset; there should be specific encouragement for precisely that type of diversity throughout the nation. The overall system should evolve naturally, incorporating those approaches and methods which are proven empirically to be effective; the service delivery system for the handicapped is too important a thing to be designed in an ivory tower vacuum by persons working more with inadequately investigated conceptual abstractions than with hard information.

In order for the total service delivery system for the handicapped to be maximally effective, however, the loop must be closed. If the service delivery system for the handicapped is to be regarded as being principally responsible for assuring that the handicapped derive optimum benefits from both specialized and generic services, the service delivery system for the handicapped must be invested with authority proportionate to this responsibility.

This means that the service delivery system for the handicapped must be able to do more than approach, beg, cajole and curse those human resources programs which are supposed to serve the handicapped as a minority group within a larger population of eligible clientele. It means that the service delivery system for the handicapped needs to have legal authority—backed by clear and continuing political commitment—to sign off on the state plans of other human services programs, procedures available for initiating meaningful reviews whenever other human services programs are not meeting their service obligation to the handicapped in an effective and substantial manner, and effective remedies for curing those performance deficiencies documented through the review processes.

Whether the kind of service delivery system for the handicapped which this paper envisions is attainable remains to be seen, but it is pointed out that a few states have already made significant beginnings toward the development of service delivery systems similar to the model advanced herein. Whether this proposed type of service delivery system could become a reality nationally is not, however, regarded as being dependent

upon the fostering of additional goodwill, empathy and enlightenment on the part of the general public and the elected public officials of this country; that understanding and basic support already exists. What is more fundamentally required for the attainment of a service delivery system for the handicapped which approximates the model proposed in this paper is for providers and recipients of services to get together—and then to put it together and to hold it together.

BIBLIOGRAPHY

1. Council of State Administrators of Vocational Rehabilitation. "Position of Council of State Administrators of Vocational Rehabilitation with Respect to Effective Vocational Rehabilitation Programs." Unpublished position paper, Washington, D.C., 1976.
2. Council of State Administrators of Vocational Rehabilitation. "The State-Federal Vocational Rehabilitation Program Looks to the Future—A Statement of Mission and Goals." Unpublished position paper, Washington, D.C., 1967.
3. Council of State Governments. Report prepared under a Services Integration Project grant from the U.S. Department of Health, Education and Welfare. *Human Services Integration—State Functions in Implementation.* Lexington, KY: Council of State Governments, 1974.
4. Mallas, Aris A. *An Evaluation of the Organization of State Programs To Serve the Blind . . . And a Suggested Evaluation Sequence.* Vol. I. Austin, TX: Management Services Associates, Inc., 1975.
5. U.S., Congress, Senate. *Report of the Senate Committee on Labor and Public Welfare.* Senate Report No. 94–168. Harrison A. Williams, Jr., chairman. Washington, D.C.: U.S. Government Printing Office, 1975.
6. Risley, Burt L., and Hoehne, Charles W. "The Vocational Rehabilitation Act Related to the Blind: The Hope, The Promise—And the Reality." *Journal of Rehabilitation.* September-October, 1970.
7. Risley, Burt L. "The Case for Separate Programs for the Blind." State Commission for the Blind: Austin, TX., 1965.
8. Committee on Statement of Mission and Goals of National Council of State Agencies for the Blind. "The Mission and Goals of the National Council of State Agencies for the Blind—A Statement of Organizational Policies and Principles." Unpublished paper, Washington, D.C., 1967.

CIVIL RIGHTS

Awareness Paper Prepared By

Louis T. Rigdon, Esq.
White House Conference on Handicapped Individuals
Washington, D.C.

ACKNOWLEDGMENT

The White House Conference on Handicapped Individuals wishes to thank the following council members for their extensive assistance: Dr. Paul Hoffman; Jesse Brown; Albert Pimentel; Burt Risley and Ms. Jayne Shover. Major contributors to this paper were: Ms. Judy Heumann; Irvin Rutman; Ms. Rita McGaughey; Ms. Marie Thompson; Eric Dibner; John McLaughlin. Special thanks go to members of the Technical Review Team: Ms. Marcia Burgdorf, Director, Developmental Disabilities Law Project; Ms. Eunic Fiorito, Mayor's Office for the Handicapped, (New York); Dr. James Folsom, Director, Rehabilitation Medicine and Surgery, Veterans Administration; Lex Frieden, University of Texas; and Ms. Essie Morgan, Chief, Socio-Economic Rehabilitation and Staff Development, Spinal Cord Injury, Veterans Administration, and Mrs. Arlene Williams, Staff, White House Conference.

This Awareness Paper was prepared by subject-matter experts to serve as one resource for discussions leading to solutions of problems facing all individuals with mental and physical handicaps. This Paper was not intended to be all-inclusive, but was designed to stimulate discussions.

ACKNOWLEDGMENT OF SOURCES

To a significant extent this paper consists of excerpts of articles from law reviews and other periodicals and reports. The source of each excerpt will be shown at the beginning of each particular section. The quotation marks around the excerpts included and the footnotes have been omitted.

I want to express my appreciation to the authors whose research products have been used in this paper. A bibliography of the sources relied upon will appear at the end of the paper.

Louis T. Rigdon

TABLE OF CONTENTS

	Page
Introduction: Human and Civil Rights of All Persons	397
Overview of Unequal Treatment	397
Civil Rights Statues	399
Federal	399
State and Local	400
Other Federal and State Statutes	400
Education—Right to Equal Educational Opportunity	401
The Right to Equal Employment Opportunities and Just Payment for Labor	401
Freedom to Move About—Architectural and Transportation Barriers	402
Architectural Accessibility	403
Transportation Accessibility	404
Right to Treatment in a Minimally Restrictive Environment	404
The Right to Refuse Treatment and The Right to Be Free From Experimentation	407
The Right to Live in the Community	407
The Right to Privavcy and Confidentiality	407
The Right to Vote	407
The Right to Marry, Procreate, and Raise Children	408
Right to Nondiscriminatory Financial Transactions	409
Handicapped Persons are Entitled to Equal Projection of the Laws	409
Appendix	410
Selected Bibliography	418
Addendum	419
Civil Rights—Responsible Legal Action and Advocacy	419
Lawyers and Legal Advocacy	419
HEW Proposes Regulations for Section 504	419
Architectural Accessibility	421
Transportation Accessibility	422
Disenfranchisement of the Mentally Handicapped Citizen	423
Selected Bibliography	424

INTRODUCTION: HUMAN AND CIVIL RIGHTS OF ALL PERSONS

The Declaration of Independence proclaims that all men are created equal and that they possess certain unalienable rights, such as life, liberty, and the pursuit of happiness. This means that all men are equal or the same in being human beings. It is an affirmation of the community of human beings. Human beings have certain rights inherent in their humanness which cannot be alienated or taken away.

In this country, most human rights find their specificity in the civil rights based in Federal and state constitutional and statutory provisions. A civil or legal right is one which may be ultimately enforced in a court of law.*

Physically and mentally disabled or handicapped individuals have both different and similar problems as they relate to the state (used generically) and to other so-called normal individuals. Most physically or mentally disabled persons and their advocates object to the terms "handicapped" or "retarded" because they tend to stress the differences rather than the characteristics which these persons share with others. Moreover, the term "disability" is preferred over "handicapped." A disability connotes more the condition which the person has whereas "handicap" refers to an impediment caused by the environment.

Nevertheless, "handicapped" is currently both the accepted everyday expression and a common statutory term for describing persons with disabilities. For the sake of uniformity, the word "handicapped" will be used in this paper. (See Appendix I.)

*Rights have their source in the following:

1. United States Constituion concepts such as the right to equal protection of the law, to life, liberty, and property protected by due process of law, and to those guarantees granted in the Bill of Rights and the Thirteenth, Fourteenth, Fifteenth, Nineteenth, and Twenty-fifth Amendments;

2. Federal legislation and regulations–The Rehabilitation Act of 1973 and Amendments of 1974, the Fair Labor Standards Act, the Elementary and Secondary Education Act, the Architectural Barriers Act, and the Education of All Handicapped Children Act of 1975, and the Developmental Disability Facilities and Bill of Rights Act of 1975.

3. State constitutions creating legal rights to equal public education and forbidding discrimination against a person because of a handicapping condition;

4. State legislation and regulations–civil rights, employment, education, public housing, community and residential service programs, public accommodations, curb-cut and ramp laws.

Many in government as well as in private enterprise do not want what should be the civil rights of "handicapped" individuals to be enforced for the same reasons that the civil rights of others have been difficult to enforce: because the group needing these rights is culturally out of the mainstream and is often misunderstood; because it will cost money; and, it will be inconvenient and troublesome. Notwithstanding this vestigal attitude, physically and mentally handicapped persons have the right to make choices and decisions which affect their lives. This dignity of risk is an integral part of being a person in a community of persons. It is clear that the lack of enforcement provisions in existing laws and regulations as well as knowledgeable advocates have hampered implementation efforts.

Congress, in Public Law 93-516 found that it is critically important to provide *all* handicapped individuals equality of opportunity, equal access to all aspects of society, and equal rights secured by the Constitution. Participants in the White House Conference on Handicapped Individuals are directed to make recommendations to effectuate the objective of complete integration of *all* individuals into normal community living, working, and service patterns. To assist participants in their consideration of recommendations, this awareness paper attempts to lay a foundation of understanding of the range of areas of concern.*

OVERVIEW OF UNEQUAL TREATMENT†

Historical and present-day examples of discriminatory treatment afforded handicapped people are not difficult to find. Most states either have or had statutues providing for the involuntary sterilization of mentally handicapped and certain physically handicapped citizens. In the late 1950's, 28 states had sterilization statutes, and 17 of those laws specifically included persons with epilepsy, as well as the mentally ill and mentally retarded.

Many states have prohibitions on marriages between handicapped persons. Most states proscribe marriage where one of the parties is mentally ill or mentally retarded, and some also

*The United Nations General Assembly on December 9, 1975, adopted THE DECLARATION ON THE RIGHTS OF DISABLED PERSONS (See Appendix II).

†M.P. Burgdorf and R. Burgdorf, *Santa Clara Lawyer*, p. 861 *et seq.*

limit the right of physically handicapped people to marry. At least 17 states have had prohibitions against marriage by persons with epilepsy.

A number of states restrict or deny the right of mentally handicapped people to enter into contracts.

A blatant example of discrimination against handicapped people is found in a federal statute outlining qualifications for admission of aliens to the United States. The enforcement of these sections has blocked the entry into this country of numerous persons afflicted with various types of physical and mental disabilities.

Handicapped persons are routinely denied other rights which most members of our society take for granted, including the right to vote, to obtain a driver's license or a hunting and fishing license, to enter the courts, and to hold public office.

Often state laws and practices concerning handicapped people can only be termed "bizarre." One collection of strange provisions which discriminate against physically-handicapped persons can best be described as "ugly laws." Until recently, the Chicago Municipal Code provided

> no person who is diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object or improper person to be allowed in or on the public ways or other public places in this city, shall therein or thereon expose himself to public view, under a penalty of not less than one dollar nor more than fifty dollars for each offense.

Columbus, Ohio; Omaha, Nebraska; and other cities still have similar ordinances in effect.

Employment is one area of particularly widespread discrimination against those with handicaps. Only a small percentage of the handicapped Americans who could work if given the opportunity are actually employed. Transportation, physical barriers, and employers' prejudices have combined to deny the handicapped person access to many avenues of employment available to other citizens. It is estimated that only one-third of the blind persons of working age in this country have jobs. Only 47% of the paraplegics of working age are employed. And, only a handful of the persons of working age with cerebral palsy have been able to secure employment.

These figures are dismal indeed when one considers that the majority of unemployed handicapped persons are quite capable of competing in the job market. Numerous studies indicate that handicapped workers perform just as well, if not better, than fellow non-handicapped workers. But employers continue to discriminate against handicapped job applicants.

Denial of employment opportunities is especially outrageous in regard to handicapped veterans. While the unemployment rate for Vietnam Era veterans at the end of 1971 was estimated at 8.8%, 87.7% of the handicapped veterans were unable to find jobs. The disabled Vietnam veteran "seeks employment and is rebuffed either by the private employer as incompetent or by his Government as being essentially unplaceable."

An additional problem is that those handicapped persons who do manage to find employment tend to be channeled into unskilled, low-paying positions involving monotonous tasks.

Transportation is another major area of current discrimination. In our mobile society, handicapped people are too frequently denied access to public transportation. The Air Traffic Conference has promulgated the following rule concerning service to handicapped passengers by member airlines: "Persons who have malodorous conditions, gross disfigurement, or other unpleasant characteristics so unusual as to offend fellow passengers should not be transported by any member." Such vagueness permits airlines to effect policies of discrimination toward handicapped persons.*

Moreover, a Civil Aeronautics Board regulation has been interpreted by most airlines to require that an attendant accompany all passengers in wheelchairs, whether or not these passengers are capable of caring for themselves in flight.

Similar discriminatory practices have occured on or in surface transportation systems like interstate bus lines. Railroads have also been

*One airline will not allow an unaccompanied blind person to sit next to a person of the opposite sex; another refuses to accept persons with epilepsy as passengers; at least seven airlines refuse service to mentally ill passengers; and one airline expressly excludes mentally retarded people from passenger service.

guilty of unequal treatment of handicapped persons, particularly in requiring that a fare-paying attendant accompany all passengers in wheelchairs, regardless of the passenger's ability to attend himself.

Even where transportation agencies do not have active policies which restrict the travel rights of handicapped passengers, architectural impediments and physical obstacles may render use of transportation facilities impossible for various groups of handicapped citizens. The "fundamental right to travel" has little meaning if architectural barriers render a person unable to enter buses, trains, planes, or transportation terminals.

In some instances, discriminatory practices threaten the lives of handicapped individuals. A number of situations have occurred in which medical personnel or parents of handicapped children have made no effort to provide handicapped patients with lifesaving medical services which would be administered as a matter of course to non-handicapped patients.

Many cases involving both physically and mentally handicapped infants who have been "allowed to die" have been reported. One observer estimates that unnecessary deaths of handicapped babies in the United States may number in the thousands each year. Recently, advocates for handicapped infants have successfully challenged the legality of denying medical treatment to such children. However, the fact that such events occur in a country which esteems life as an "inalienable" right is frightening evidence of the discriminatory and inequitable treatment afforded handicapped people.

CIVIL RIGHTS STATUTES

Federal:

While there have been unsuccessful attempts to include persons with physical and mental disabilities as a separate category in the Federal Civil Rights Act of 1964, Section 504 of the Rehabilitation Act of 1973 is the nearest existing federal law in the nature of civil rights statute applicable to handicapped individuals.

Section 504 provides that "no otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, denied the benefits of, or be subject to discrimination under any program or activity receiving federal financial assistance."

The Rehabilitation Act of 1973 omitted provisions describing the implementation and enforcement procedures which would be necessary to carry out Section 504. However, Congress stated that the language was mandatory and envisions the implementation of a Compliance Program which was similar to Title VI of the Civil Rights Act of 1964 and Section 901 of the Education Act Amendments of 1972 (relating to sex).

Because of the Department of Health, Education, and Welfare's experience in dealing with handicapped persons and with the elimination of discrimination in other areas, Congress desired that HEW assume responsibility for coordinating the Section 504 enforcement effort. (See Appendix III).

While the Department of Health, Education, and Welfare had not published proposed Section 504 regulations at the time this paper is being written, the President on April 28, 1976 issued Executive Order 11914, entitled "Nondiscrimination with Respect to the Handicapped in Federally Assisted Programs." Under this Executive Order, the Secretary of Health, Education, and Welfare is directed to coordinate implementation of Section 504 by all Federal departments and agencies empowered to extend Federal financial assistance to any program or activity.

The Secretary of HEW shall:

1. Establish standards for determining who are handicapped individuals and guidelines for determining what are discriminatory practices, within the meaning of Section 504.
2. Assist Federal departments and agencies to coordinate their programs and activities and shall consult with such departments and agencies, as necessary, so that consistent policies, practices, and procedures are adopted with respect to the enforcement of Section 504.

Each Federal department or agency must issue rules, regulations, and directives consistent with the standards and procedures of HEW. The Secretary of HEW may adopt regulations necessary to carry out his responsibilities. (See Appendix IV.) Legal action has been initiated (*Cherry v. Matthews*) to force the issuance of Section 504 regulations. Issues involved in developing regulations to enforce Section 504 have

included the economic impact or cost and benefits of such action, the interrelationship of the concepts of discrimination, accommodation, and affirmative action and architectural barriers, and the meaning of "otherwise qualified handicapped individuals." (See Appendix V.)

State and Local

Illinois and Florida are the only states which have constitutional provisions prohibiting discrimination. In Illinois, discrimination in the sale and rental of property and in employment against physically and mentally disabled persons is forbidden. In Florida, no right can be denied on the basis of a physical handicap.

Several states and cities like Iowa, California, Kansas, Indiana, Wisconsin, Washington, New York, New Jersey, the District of Columbia, and New York City have enacted civil rights or anti-discrimination in access to public accommodations, employment, rental or leasing or other transactions involving housing. Some statutes, like that of California, protect the right of access to streets, highways, and public conveyances. The Civil Rights Act of the State of Washington bans discrimination in credit and insurance transactions. White can laws secure the right of blind and other physically handicapped persons to use sidewalks, streets, buildings, and transportation especially with the use of a guide dog. (See Appendix VI.)

State statutes generally establish a state-wide commission to hear and receive complaints and to enforce prohibitions. State prohibition does not pre-empt local laws not inconsistent with the state law that deals with the same subject matter.

Other Federal and State Statutes

The Rehabilitation Act of 1973 (Public Law 93-112),* in addition to the affirmative action programs and anti-discrimination provision, requires the state vocational rehabilitation agencies to develop individualized written rehabilitation programs on each client. The program is to be promptly developed by the rehabilitation counselor and the handicapped individual or his parent or guardian spell-out the terms, conditions, rights, and remedies under which services are provided to the individual giving the long and immediate goals to be attained. Periodic review and internal safeguards are provided for.

Newly enacted federal and state developmentally disabled and mental retardation laws have established bills of rights to safeguard the human dignity of the persons involved.

Client assistance projects are designed to advise clients on available benefits and help them in their dealings with rehabilitation agencies. The Rehabilitation Act Amendments of 1974 emphasize reporting and analyzing of the reasons for determinations of ineligibility for services and for re-evaluating individuals refused services to ascertain whether they have any potential for achieving vocational goals. Clients must be given opportunity to participate in determination of service ineligibility and be advised of their rights and the remedies available to them. Physically and mentally handicapped persons who meet the statutory definitions of "handicapped individuals, severely handicapped individuals, or developmentally disabled individuals" can qualify for benefits, assistance, and programs under the Housing and Community Development Act of 1974, Social Security Acts, Supplementary Security Income, National Health Planning and Resources Development Act of 1974, Developmental Disability Assistance and Bill of Rights Act of 1975, and the Education of All Handicapped Children Act of 1975.

History shows that effective advocates are vital in achieving and implementing the rights of any group. Advocacy programs for both physically and mentally handicapped children and adults have been supported by the Federal government and other groups. With the passage of the Developmentally Disabled Assistance and Bill of Rights Act of 1975 (Public Law 94-103), it appears that the advocacy system for persons with disabilities will be broadened. This Act requires that states receiving allotments thereunder establish a system to protect and advocate the rights of persons with developmental disabilities with the authority to pursue legal,

*The Rehabilitation Act of 1973 defined "handicapped individual" as any individual who (a) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment, and (b) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services provided under Title I and II of that Act.

The Rehabilitation Act Amendments of 1974 (Public Law 93-516) changed the definition for purposes of Titles IV and V to any person who (a) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (b) has a record of such an impairment, or (c) is regarded as having such an impairment.

administrative, and other appropriate remedies to protect such persons receiving treatment services or habitation within the State. The advocacy system must be independent of the State agencies providing the treatment services and habitation.

Hopefully, this new Federal legislative program and other publicly and privately supported activities will assist efforts to develop strategies for the establishment of a coordinated nationwide legal advocacy network for persons with disabilities.

EDUCATION–RIGHT TO EQUAL EDUCATIONAL OPPORTUNITY*

The United States Supreme Court in 1954 in *Brown v. Board of Education*, 347 U.S. 438, placed into American Constitutional Law the cornerstone of the concept of the right to an equal educational opportunity. Every child, including every handicapped child, must be allowed access to an appropriate program of free public education suited to his needs. The application of this principle condemns as unconstitutional any attempt to exclude any handicapped child or group of such children from the public education system. "Zero reject" public education is mandated.

In *Pennsylvania Association for Retarded Children v. Pennsylvania*, 334 F supp. 1257 (E.D. Pa. 1971) and 343 F Supp. 279 (E.D. Pa. 1972), hereinafter PARC, the principle of equal educational opportunity was applied to all mentally retarded children in the state of Pennsylvania.

In 1972 the principles of the PARC case as to mentally retarded persons were applied to children with all types of handicaps in the case of *Mills v. Board of Education of District of Columbia* (348 F. Supp. 866 (DDC 1972)). The District Court ruled that the exclusion of handicapped children from the public school system was violative of due process and equal protection. The court ordered

> that no child eligible for a publicly supported education in the District of Columbia public schools shall be excluded from a regular school assignment by a rule, policy, or practice of the Board of Education of the District of Columbia or its agents unless such child is provided (a) adequate alternative educational services suited to the child's needs which may include special education or tuition grants, and (b) a constitutionally adequate prior hearing and periodic review of the child's status, progress, and the adequacy of any educational alternative. 348 F. Supp. at p. 878.

The Mills court based its decision on the due process and equal protection clauses of the U.S. Constitution, defeating the concept of uneducability and making its ruling applicable regardless of degree of type of exceptionality and regardless of the fiscal impact on the school system.

Courts in approximately 40 states have followed the *PARC* and *Mills* decisions. Most notable of these successive cases is *In re G.H.* 218 N.W. 2d 441 (1974) where a state Supreme Court held that administrative buckpassing as to whose responsibility it was to educate a handicapped child violated the rights of that child. (See Appendix VII.)

The Constitutional doctrine has been best explained by Attorney Paul Dimond. He wrote: "First, the unjustified exclusion of any child from all public schooling denies to that child the equal protection of the laws when the state makes the opportunity freely available to other children. Second, the operation of our unfair procedure in the stigmatization by public authority of any person or the denial to him of any public good denies the process due each person under the Fourteenth Amendment. Such a stignatization and denial is involved in labeling children as 'exceptional,' 'retarded,' or 'handicapped,' and placing them in special classes, or excluding them from schooling entirely. These two rights, equal protection and due processs, merge to form the emerging constitutional right to an education, which guarantees to every child a minimally adequate publicly supported educational opportunity."

THE RIGHT TO EQUAL EMPLOYMENT OPPORTUNITIES AND JUST PAYMENT FOR LABOR*

There is no constitutional right which guarantees a person a job. However, the total elimination of handicapped persons from consideration

*R. Burgdorf, Jr., NCLH Paper and Laski, at p. 20.

*R. Bergdorf, Jr., NCLH Paper pp. 10-12 and GAO Report (1974) pp. 1-3.

for a job may be constitutionally prohibited. While a person may not be absolutely entitled to employment, he cannot be arbitrarily and unfairly discriminated against. Denial of the right to equal employment opportunities may violate state and federal constitutional guarantees of equal treatment.

As early as 1915 the United States Supreme Court declared that

> the right to work for a living in the common occupations of the community is of the very essence of the personal freedom and opportunity that it was the purpose of (the Fourteenth) Amendment to secure. *Truax v. Reich*, 239 US 33, 41, (1915).

This is a new area of litigation, and judicial precedent directly on point is only beginning to develop.

The right of handicapped persons to be free from discriminatory practices concerning hiring, firing, and promotions is closely related to a right about which the courts have ruled: that is, the right to just compensation for labor. In the past many residential institutions for handicapped people have required the residents to perform strenuous physical labor for no pay, under the guise of "work therapy." This slave labor, termed "peonage" has been challenged in the courts. In a landmark decision, *Souder v. Brennan*, 367 F.Supp. 808 (D.D.C. 1973), the U.S. District Court for the District of Columbia ruled that residents of such institutions are governed by minimum wage and overtime compensation provisions. Henceforth, if residents are forced to work, they will be guaranteed a wage.

Since 1942, the Civil Service Commission and the Congress have taken positive actions to remove barriers in employing the handicapped.

The rehabilitation Act of 1973 (PL 93-112) imposes additional review and reporting requirements on the CSC and other federal agencies relative to promotion and support of employment opportunities for the handicapped.

Specifically, the Act provides for establishing an Interagency Committee on Handicapped Employees to provide a focus for federal employment of handicapped individuals and to insure that the special needs for such individuals are met. The Act requires federal agencies and state vocational rehabilitation agencies to establish affirmative action programs for employment of handicapped individuals. Section 503 of the Act provides that any contract in excess of $2500 entered into by a federal department or agency for the procurement of personal property and nonpersonal services (including construction) for the United States shall contain a provision requiring that in employing persons to carry out such contract the party contracting with the United States shall take affirmative action to employ and advance in employment qualified handicapped individuals. This section is also applicable to subcontract in excess of $2,500. The President was directed to implement the provisions of this section by promulgating regulations within 90 days after enactment.

If a handicapped individual believes any person has failed or refuses to comply with the provisions of this contract, such an individual can file a complaint with the Department of Labor. The Department shall promptly investigate such complaint and shall take such action thereon as the facts and circumstances warrnat, consistent with the terms of such contract and the laws and regulations applicable thereto.

Requirements of this section may be waived in whole or in part by the President with respect to a particular contract or subcontract in accordance with the guidelines set forth in regulations which he shall prescribe when he determines that special circumstances in the national interest so require and states in writing his reasons for such determination.

The Vietnam Era Veterans' Readjustment Assistance Act of 1974 mandated a similar affirmative action program for disabled veterans and veterans of the Vietnam Era. Regulations promulgated by the Department of Labor were proposed to assure compliance with Section 503 and Section 401 of the Vietnam Era Veterans' Readjustment Assistance Act of 1974. Section 503 regulations were put into effect with their publication on April 16, 1976. The responsibility for enforcement of Section 503 has been placed in the Office of Federal Contract Compliance Programs of the Department of Labor. (See 41 FR 16147-16155, April 16, 1976).

FREEDOM TO MOVE ABOUT— ARCHITECTURAL AND TRANSPORTATION BARRIERS*

Freedom to move about with the least amount of avoidable restrictions is essential to

*GAO Report at p. 1-5; Note GEO L J AT p. 1509-1512; Actenberg at p. 196; Farber at p. 112.

life itself and all of its activities. Architectural, transportation, and communication barriers affect one's education, health, recreation, employment, and social relationships. To a substantial extent these barriers are what actually "handicap" persons who have physical disabilities.

Architectural Accessibility

Handicapped individuals are presently excluded from many public buildings by architectural barriers ranging from monumental staircases to 6" curbs. If handicapped individuals cannot enter and use public buildings, they cannot easily vote, obtain governmental services, conduct business, or become independent and self-supporting. Efforts to enhance talents and more job skills become meaningless at the jobsite if the usual places of business are inaccessible.

The Architectural Barriers Act of 1968 is aimed toward the elimination of structural barriers and to promote accessibility in public buildings constructed, leased, altered, or financed by or on behalf of the United States subsequent to the date of enactment. However, this Act does not effectively accomplish that which it purports to do. As a result of easily avoidable ambiguities in the statutory language and unsupervised administrative dilution even where the statute does seem clear and unequivocal on its face the Act simply does not, in legal or practical effect, "insure that physically handicapped persons will have ready access to, and use of, (federal) buildings."

By 1974 all 50 states and the District of Columbia had, through legislation, executive directives, or building codes, required the elimination of architectural barriers in public buildings. Many state and local architectural barriers laws mandated standards of accessibility for both publicly funded buildings and publicly used by privately owned buildings. The Federal Highway Act Amendments of 1973 and many state and local acts provide for curb-cuts and ramps. Standards of accessibility followed by barrier laws encompass requirements for visual and auditory communication devices. Unlike the Federal Government, most state laws do not establish a special body to coordinate enforcement of and compliance to standards. Instead, they usually leave such compliance enforcement to state and local agencies charged with other responsibilities, such as the fire marshall. At least one state, however, Massachusetts, has established an Architectural Barriers Compliance Board.

An important recent development in the area of architectural barrier law was the creation of an Architectural and Transportation Barriers Compliance Board by the 93d Congress. While it is too early to assess the Board's impact on the administration of the Architectural Barriers Act of 1968, the Board certainly has the potential to effect a major improvement in the Act's credibility.

With respect to public buildings, federal law requires that all new federal and federally assisted facilities designed for public use be readily accessible; however, there is no provision for existing structures. State statutes addressing the problem of architectural barriers also generally ignore the need for modifications of existing buildings. It should be noted that the Supreme Court long has recognized that citizens have the right to come to their "seats of government" to transact business and petition for redress of grievances. This freedom to petition is protected by the First Amendment and applies to all branches of government, including the administrative agencies. (See *Friedman v. City of Guyahoga*, Case No. 895961 (Ct. of Common Please, Cuyahoga City, Nov. 15, 1972)–Appendix VIII.)

Since the physical barriers which impede the handicapped individual's access generally exist because of poor planning choices and serve no useful purpose, they may be attacked as unreasonable and discriminatory. States have the alternative when building facilities to use designs which would make facilities fully accessible at similar cost. By an official choice of construction, a state may possibly infringe upon the rights of handicapped persons; therefore, the state has a duty to eliminate all such impediments to the free exercise by handicapped individuals of their rights. The courts, however, will tend to order building modifications, costly or otherwise, when Bill of Rights freedoms are involved.

In *Washington Urban League v. Washington Metropolitan Area Transit Authority* (D.D.C. 1973),* Judge William Jones enjoined the Washington Metro Subway System from operating

*Public Law 91-205 (1970) made 1968 Federal Barriers Act applicable to Washington, D.C. Metro Subway facilities.

commercially until it was made accessible to physically handicapped persons by the installation of vertical elevators. Since the Metro case centered on a question of statutory interpretation, the defendants' arguments and actions, interpreting handicapped persons out of the transportation system, are instructive as to the price handicapped citizens have had to pay for reliance on legislative measures to achieve reform and augment services. The history of discrimination in generic programs leading to specialized legislation to provide for handicapped persons, requiring specialized funding, which may or may not be provided, has led to some peculiar attitudes and assumptions relating to rights of handicapped persons under statute.

In reviewing implementation of state statutes, it is possible to derive two widely practiced rules of construction which, until recently, have gone unchallenged. First, that general laws providing benefits and protection to all citizens implicitly exclude handicapped persons. Second, that mandatory language in specialized legislation is something less than mandatory when applied to handicapped persons.

Architectural barriers legislation is but another example. While provisions vary from state to state, coverage is generally limited to new public buildings, enforcement is diffuse and weak, and the statutes are riddled with waiver clauses. Thus, it is important for handicapped persons to establish that these statutes are in no way pre-emptive—that they do not define the limits of right to access to public buildings and accommodations.

Transportation Accessibility

The right to travel and to use the instrumentalities of interstate commerce are fundamental rights under the Constitution. The issue here is how this right and other First Amendment rights affect transportation of handicapped individuals on intercity buses, rail, airplanes, and other forms or instrumentalities of transportation. Lawsuits aimed at achieving actual accessibility in public transportation, especially for persons in wheelchairs, have been brought in New York, Washington, California, Alabama, Wisconsin, Michigan, and Maryland. Thus far the courts have not recognized a right to actual access by persons who use wheelchairs.

Another instance in which a federal agency has not made adequate provision for the disabled through its rulemaking authority is found in the airline situation. At the present time the Federal Aviation Agency (FAA) has yet to issue permanent provisions which impose a duty on all interstate airlines to serve the severely disabled. Therefore, airlines' pilots and officers have had extensive discretion in determining whether to allow the disabled on airplanes. The theory behind this discretion is that disabled are most likely to be injured in a crash or will take up valuable time of the flight personnel in an emergency. The first theory disregards the disabled person's own willingness to take the risk of such danger. Each airline has instituted its own policy in this regard.

In terms of future litigation the newly proposed federal regulations may not improve the situation greatly. Under the proposed regulations, only the same number of severely disabled persons are permitted on each flight as there are emergency exits, and only one person confined to a litter is permitted per flight. The handicapped person is not allowed to sit in the seat nearest any of the exits. Another drawback of the proposed regulations is the definition of a handicapped person as "a person who may need the assistance of another person to expeditiously move to an exit in the event of an emergency evacuation." As stated by Senator Tunney, this definition is "so vague and general that anyone from one's grandmother to a skier with a sprained ankle could be classed as handicapped."

RIGHT TO TREATMENT IN A MINIMALLY RESTRICTIVE ENVIRONMENT*

The institutionalization of persons with mental disabilities, including the mentally ill and the mentally retarded, has produced an increasing amount of litigation specifying the legal rights of not only mentally disabled persons, but also physically disabled persons who are institutionalized. The legal issues involved in the institutionalization of the mentally ill frequently apply to the mentally retarded.

Legal concern with the institutionalized mentally ill has centered on those who are involuntarily committed for treatment. This is so because such commitments, in the Supreme Court's words, involve "a massive curtailment of

*Burgdorf and Burgdorf, Vol. 15, *Santa Clara Lawyer*, pp. 891-99; Klein, *Background Paper*, at app. 3-22.

liberty (by the state)," which calls into play a whole host of constitutional protections.*

Most states require that to be committed a person be "mentally ill"† and either dangerous to himself or others, or in need of treatment. Civil libertarians have argued that unless a person is physically dangerous, the state has no legitimate purpose in confining him and imposing treatment against his will. A few federal courts have accepted this constitutional attack on the *parens patriae* (substitute parent) power of the states, thus effectively limiting civil commitment to those who are dangerous. Several states have also amended their statutes to conform with this position.

The fact that handicapped persons are confined to state institutions solely because of their mental or physical disabilities, coupled with the growing realization that these institutions do little to improve the lot of such persons, has produced a recent upsurge in litigation. In the last decade, reformers have filed lawsuits challenging conditions inside residential institutions and the very existance of the institutions themselves.

Rouse v. Cameron 373 F.2d 451 (D.C. Cir. 1966) was one of the first cases dealing with the right to treatment, a concept articulated in the 1960's by Dr. Morton Birnbaum. The holding in *Rouse* was that any involuntarily committed person has a right to treatment (under a Washington, D.C., statute which mandated treatment for persons committed to public hospitals because of mental illness).

In 1971 the important case of *Wyatt v. Stickney*‡ focused squarely on inhumane conditions at three Alabama institutions. The *Wyatt* court held that

> to deprive any citizen of his or her liberty upon the altruistic theory that the confinement is for humane therapeutic reasons and then fail to provide adequate treatment violates the very fundamentals of due process.

Relying upon *Rouse*, the *Wyatt* decision declared that where patients were involuntarily committed for treatment purposes through non-criminal procedures lacking the constitutional safeguards afforded to criminal defendants, they

> unquestionably (had) a constitutional right to receive such individual treatment as will give each of them a realistic opportunity to be cured or to improve his or her mental condition. The purpose of involuntary hospitalization for treatment purposes is *treatment* and not mere custodial care or punishment. This is the only justification, from a constitutional standpoint, that allows civil commitments to mental institutions such as the one involved here.

The *Wyatt* court specified three fundamental elements of the right ot treatment: a psychologically and physically humane environment, qualified staff in numbers sufficient to administer adequate treatment, and individualized treatment plans. Relief was founded on the right to due process, but the court stated that denial of equal protection and infliction of cruel and unusual punishment could provide additional grounds.

The *Wyatt* opinion also emphasized the mental patient's right to be treated in the *least restrictive setting.* The implication was that a person should not be subjected to institutionalization, which involves extensive curtailment of liberty, if he can be treated while he remains in the community. The evidence presented to the *Wyatt* court indicated that long-term institutionalization in itself leads to deterioration and decreases the chance that an individual will be able to cope successfully in the outside world.

While the *Wyatt* case attempted to remedy the inhumane conditions in Alabama institutions, it did not deal with the underlying problem: the *existence* of segregated facilities. The formulation of elaborate standards for record keeping, staffing ratios, living conditions and disciplinary policies *implies* the necessity for the existence of such institutions. *Wyatt* never

*Voluntary patients, on the other hand, do not involve a state deprivation of liberty and so do not appear to raise significant legal issues. It must be recognized, however, that many "voluntary" patients are effectively coerced by threat of commitment, therefore some of the rights of involuntary patients are equally applicable to voluntary patients. Courts have held that "voluntary" commitment of a child by his or her parents is *not* truly voluntary commitment.

†Commitment statutes uniformly fail to provide any concrete meaning for this operative term. Major legal attack has not come on this score.

‡325 F.Supp. 781, *on submission of proposed standards by defendants*, 334 F.Supp. 1341 (1971), *enforced*, 344 F.Supp. 373 (M.D. Ala. 1972).

confronted the basic issue of whether any large-scale, geographically remote, full-time residential institution could *beneficially affect* the lives of its residents.

There is concern that simply improving the conditions at residential institutions for handicapped individuals will guarantee their continued existence. However, serious problems would arise if the residents of existing institutions were released into the community without any provision for appropriate community services. The fact that this might occur has caused many institutional personnel and families of the residents to endorse adamantly the continued existence of institutions while ignoring the serious violation of rights that residents suffer.

In *Welsch v. Likins* (373 F.Supp. 487 (D.Minn. 1974)) the court held that persons civilly committed for reasons of mental retardation had both a statutory and, under the due process clause, a constutional right "to adequate care and treatment designed to give each person a realistic opportunity to be cured or to improve his or her mental condition." *Welsch* also directed state officials to make good faith efforts to place mentally retarded persons in settings that would be suitable and appropriate to their mental and physical conditions. Although *Wyatt* enunciated the right to treatment in the least restrictive environment, it did not impose this responsibility upon state officials as *Welsch* did.*

The United States Supreme Court was asked to rule upon the issue of whether there exists a constitutional right to treatment in *O'Connor v. Donaldson* (95 S.Ct. 2485 (1975)). The Court chose not to deal directly with the issue of a right to treatment and, instead, addressed the basic underlying issue: the right to be free from involuntary institutionalization.

Mr. Donaldson had been involuntarily confined in a state mental hospital for 15 years. Throughout his confinement, Donaldson repeatedly demanded his release, stating that he was dangerous to no one and that in any case the hospital was not providing any treatment for his supposed illness. Donaldson brought a civil rights action, contending that the superintendent and other members of the hospital staff, named as defendants, had intentionally deprived him of his constitutional right to liberty. The jury returned a verdict in favor of Donaldson and assessed both compensatory and punitive damages against the defendants. The Court of Appeals for the Fifth Circuit affirmed the lower court finding. Evidence presented at the trial showed that Donaldson's confinement was a simple regime of enforced custodial care, not at all unlike the so-called "treatment" programs which thousands of mentally ill, mentally retarded, and other disabled persons currently receive in state institutions. Since the evidence also showed that Donaldson was not, nor had ever been, dangerous to himself or to others, the Supreme Court did not decide whether a person committed on grounds of dangerousness has a "right to treatment." The Court attacked the basic premise of institutionalization; that is, the segregation of nondangerous handicapped persons: "A finding of 'mental illness' alone cannot justify a state's locking up a person against his will and keeping him indefinitely in custodial confinement." The Court held that "incarceration is *rarely if ever* a necessary condition for raising the living standard of those capable of surviving safely in freedom on their own, or with the help of family or friends." The Court concluded that even where confinement was originally constitutionally justified, it cannot continue after the need for confinement no longer exists.

In this landmark decision the Supreme Court delivered a significant blow to the widespread state practice of institutionalizing handicapped persons. But although it attacked the current legal and philosophical presumptions justifying institutional confinement, it did not address the problem of formulating acceptable criteria for commitment in those limited cases where it would be legally permissible. Several lower federal courts, however, have spoken to precisely this issue, the constitutional standards for civil commitment.

In *Lessard v. Schmidt** and *Bartley v. Kremens*,† the courts significantly restricted the criteria under which either an adult or a child can be constitutionally committed to a state institutional facility. There must be full procedural due process as well as a finding of dangerousness and a prior exhaustion of all the

*In *Dixon v. Weinberger* (D.D.C., Dec. 1975), the court ruled that patients in the District of Columbia have a statutory right to confinement in the least restrictive facility.

*349 F.Supp. 1078 (E.D.Wis.1972), *vacated and remanded for more specific order*, 414 U.S. 473, *ordered accordingly*, 379 F.Supp. 1376 (1974).

†44 U.S.L.W. 2063 (E.D.Pa., July 24, 1975).

less restrictive alternatives. Implementation of these new commitment standards will probably result in the institutionalization of far fewer handicapped persons. States must break with the traditional "treatment" model of providing residential programs services in institutions and return handicapped persons to the community.*

The Right to Refuse Treatment and the Right to be Free From Experimentation

While the right to treatment was gaining substantial recognition, civil liberties advocates began to question the propriety of the right in that it implies that if treatment is provided, patients can be denied their liberty. More important is the right to refuse certain treatment, particularly those thought to be "hazardous" or especially "intrusive," such as psychosurgery, electroshock therapy, aversive behaviour modification conditioning, and chemotherapy. Somewhat related to the issues of the right to refuse treatment is the question of experimentation imposed upon hospitalized populations. Recent revelations, including those regarding the use of LSD on unknowing mental patients, have led to extensive federal regulation, particularly by HEW, of experimentation on human populations. The general regulations, applicable to all experiments involving HEW funding, were promulgated in 1974, and require careful procedures to insure that participant consent is both voluntary and informed. HEW is also in the process of promulgating additional regulations to govern especially vulnerable populations such as the hospitalized mentally ill.

The Right to Live in the Community

The development of community-based residential facilities for those needing some form of sheltered care has often been frustrated by localing zoning ordinances which either restrict "medical facilities" from residential neighborhoods or limit the number of unrelated adults allowed to live together in such neighborhoods.

Under current legal standards, states and localities are given broad latitude in matters relating to zoning. In a recent Supreme Court case involving a constitutional challenge to a restrictive zoning ordiance by several unrelated adults who were living together, the Court made clear that such restrictions were within the legislative prerogatives of local governments. (*Village of Belle Terre v. Borass*, 91 S.Ct. 1536 (1974))

Despite the Broad nature of the Court's decision, legal advocates have attempted to carve out exceptions for community-based homes for the mentally disabled. They have argued that, while it may be generally permissible to restrict the number of unrelated adults who can live together, application of such a rule to the mentally ill is uniquely invidious since this population often has no other choice but to live in group homes unless they are to be kept in large hospitals. Likewise, where zoning restrictions are applicable to "medical facilities," legal advocates have claimed that community care homes are not medical but rather recreational or education and therefore allowable under the zoning ordinances.

While the legal response has not been unmixed, several state courts have held that community facilities needed are exempt from restrictive zoning provisions. This is an area, however, that seems particularly suited to state legislative reform.

The Right to Privacy and Confidentiality

A person's health status is obviously relevant to certain jobs. In order to secure this information about an applicant, employers—particularly governmental employers—request access to past treatment records. Insurance companies, too, often require a waiver of confidentiality in order to review records to insure that treatment is necessary and proper.

Legal challenges to these practices have typically rested on the constitutional principle called the *least restrictive alternative*. This principle recognizes that even though the government may have a legitimate need to know about a person's health status, it cannot satisfy this need by means that unnecessarily impinge on important individual rights such as privacy and confidentiality. Often a current medical examination, rather than access to past records, may be sufficient.

THE RIGHT TO VOTE

A long line of United States Supreme Court cases makes it clear that the right to cast one's

*It is extremely important to remember that the historical basis for institutionalization has been the notion that handicapped persons should be isolated.

ballot is a constitutionally protected right. It is becoming increasingly apparent that persons with physical or mental handicaps may not constitutionally be automatically deprived of their rightful vote. It may be leigitimate to limit the franchise to those who understand its meaning and effect, but there can be no blanket presumption that persons with any particular handicap are incapable of such understanding. In some states, residents of an institution for the mentally retarded cannot be denied the right to vote in local or national elections simply by virtue of their residence in the facility so long as they meet other requirements for voting.

With reference to physically handicapped persons, in *Selph v. Council of City of Los Angeles*, 390 F.Supp. 58 (1975), the United States District Court for the Central District of California held that the right of voting by absentee ballot constituted reasonable alternative for a handicapped person who finds that his polling place is inaccessible to him. The judge stated that a handicapped person has a constitutional right to vote but no right to insist that city officials modify all polling places within the city so as to eliminate architectural barriers. The cost of undertaking such a project would be an unfair expenditure of huge amounts of money in order to benefit a small segment of the total population even assuming the city had the ability or right to modify privately owned structures. Moreover, plaintiffs' demands would call for the modification of many polling places in precincts in which no disabled persons live. One question not dealt with by the court is what the impact its architecutral barriers stand would have on the act of seeking out a notary public to notarize an absentee ballot.

It should be noted that in voting rights discrimination cases involving race, federal courts have held that the location and adequacy of the polling place do have a significant impact on the right itself. Most states allow assistance in the booth for persons who are blind or otherwise physically unable to cast a ballot alone.

THE RIGHT TO MARRY, PROCREATE, AND RAISE CHILDREN

The Supreme Court has recognized

> "... a right of personal privacy, or a guarantee of certain areas or zones of privacy that exist under the Constitution. (the) right has some extension to activities relating to marriage... procreation, contraception... family relationships... child reading, and educations."

These rights have all been declared by the United States Supreme Court to be fundamental rights protected under the U.S. Constitution. Unfortunately, in the past these rights have frequently been denied to handicapped persons. Marriages have been prohibited or declared invalid, involuntary sterilizations have been performed, and children have been removed from the home, simply because the person involved happened to have a handicapping condition.

The blanket denial to mentally retarded or other handicapped persons of the right to marry, procreate, and raise children is a "permanent irrebutable presumption" of the type which has been condemned by the U.S. Supreme Court.

In Ohio a judge who had ordered a sterilization operation performed upon a mentally retarded girl, the doctor who performed the operation, the hospital where it was performed, and social and welfare workers who suggested the surgery, were sued for three million dollars on the basis that their action had deprived the girl of her constitutional rights. *Wade v. Bethesda*, 237 F. Supp. 671 (S.D. Ohio, 1971). The U.S. District Court for the Southern District of Ohio found that the judge was totally without authority to order the operation. Shortly thereafter the defendants agreed to settle the case voluntarily for a substantial sum of money.

In the United States adoption is purely statutory in nature. To be entitled to adopt a person must qualify under the adoption statute. In accordance with general statutory requirements, the adopting parents must be of good repute and character, be of sound mind and be financially responsible, although affluence is not required. It has been held that the fact that both parents were deaf and could not speak does not of itself disqualify them from becoming adoptive parents. While the statute may not expressly discriminate, the Agency handling the adoption considers the handicapping condition of the putative adopting parent or parents. Meanwhile, some jurisdictions subsidize the adoption of children who are handicapped in order to encourage a supposedly slow adoption process.

RIGHT TO NONDISCRIMINATORY FINANCIAL TRANSACTIONS

Prejudicial attitudes often hamper persons with disabilities from obtaining consumer credit and mortgage loans. Some states now have enacted laws prohibiting discrimination in the granting of loans or credit on the basis of physical or mental disability (Washington and California). Usually there are exceptions for persons adjudged incompetent to handle their own affairs by an appropriate judicial body.

Some handicapped individuals, like those who are blind and cannot drive, have difficulty in obtaining personal identification plates which would be similar to driver's licenses. Such identification facilitates such financial transactions as the cashing of checks. There is a move for passage of legislation at either the state or local level to establish a procedure to issue the required personal identification plates to those persons who do not and cannot drive.

HANDICAPPED PERSONS ARE ENTITLED TO EQUAL PROTECTION OF THE LAWS*

Discrimination against the handicapped may involve a "suspect" classification. The courts have found suspect classifications when the particular group involved is saddled with such disabilities, subjected to a history of such purposeful discrimination, or relegated to a position of such political weakness as to require special protection. The stigma of inferiority usually attached to such a classification has been the major determining factor in designating classifications as suspect. Handicapped groups historically have been politically weak and fragmented, and handicapped persons have been stigmatized by society with a badge of inferiority. The handicapping condition, often congenial and unalterable, has been analogized to racial classifications which almost always compel the strict standard of review. Classification of the handicapped should similarly undergo the strictest scrutiny by the courts.

If successful in establishing the handicapped condition as a suspect classification, traditional arguments offered as justifications by the state probably would not pass the compelling interest test. While a state might argue that prohibitive costs compel such classification, the Supreme Court has stated previously that constitutional rights cannot be denied merely because their protection will necessitate the expenditure of public funds. Similarly, administrative inconvenience is not a compelling interest justifying the exclusion of the physically disabled.

It is not difficult to see that handicapped people are "saddled with disabilities." By definition, a handicap is a disability. And, in addition to the physical, emotional or mental impairment, society places numerous limitations or prohibitions upon handicapped persons. Thus, the disabilities of handicapped individuals are compounded by the unequal treatment afforded them; mental, physical, and emotional disabilities are exacerbated by disabilities legally and socially imposed.

The "political powerlessness" of handicapped persons could be the subject of extensive discussion. Most mentally handicapped persons are denied the right to vote by express provisions in state constitutions and statutes. All but four states expressly exclude "idiots" and the "insane." Several states go further and exclude all those under some form of guardianship.

Physically handicapped persons are often prevented from voting by official neglect. Transportation difficulties and architectural barriers at polling placed (such as narrow doorways, flights of stairs, and revolving doors) make it difficult or impossible for those with serious mobility problems to cast their rightful ballots.

These and other problems, including restrictions upon the right to hold public office, have rendered handicapped persons almost totally "politically powerless."

At least one state court has found that handicapped persons do merit strict judicial scrutiny. In, *in re G.H.* the North Dakota Supreme court declared that under the state constitution all children had the right to a public school education and that the U.S. Supreme Court

> would have held that G.H.'s terrible handicaps were just the sort of "immutable characteristic determined solely by the accident of birth" to which the "inherently suspect" classification would be applied, and that depriving her of a meaningful educational opportunity would be just the sort of denial of equal protection

*Burgdorf and Burgdorf, Vol. 15, *Santa Clara Lawyer*, pp. 899-910; Note, Geo. L J at/pp. 1504-1505. (See Appendix IX.)

which has been held unconstitutional in cases involving discrimination based on race and illegitimacy and sex (see San Antonio Independent School District v. Rodriguez, 411 U.S. 1 (1973)).

Historically, handicapped people have been subjected to purposeful unequal treatment of considerable scope, degree, and duration. Handicapped individuals have faced and continue to face discriminatory treatment in almost every facet of life.

> The handicapped live among us. They have the same hopes, the same fears, and the same ambitions as the rest of us. They are children and adults, black and white, men and women, rich and poor. They have problems as varied as their individual personalities. Yet, they are today a hidden population because their problems are different from most of ours. (118 *Cong. Rec.* 3320 (1972)).

An important stepping-stone for handicapped persons in their rise from the long history of unequal treatment to a position of equality and dignity in our society would be a recognition by the American judicial system that handicapped persons warrant special judicial proteciton as "suspect class." Strict judicial scrutiny has already been applied to classifications based on handicapping conditions by the supreme court of one state, and the issue will undoubtedly be raised in other cases.

APPENDIX I

The dictionary defines "handicap" as "a disadvantage that makes achievement unusually difficult." When used generically, however, terms like "the handicapped" have a narrower meaning, referring to a particular type of "disadvantage"—a mental, physical, or emotional disability or impairment. Thus, a handicapped person is an individual who is afflicted with a mental, physical, or emotional disability or impairment which makes achievement unusually difficult. It should be emphasized that physical, mental, or emotional disabilities qualify as handicaps only if they hinder achievement. Moreover, the phrase "unusually difficult" makes it clear that the hindrance must be substantial; a slight inconsequential disability or impairment is not a handicap.

But to be complete, this description requires one final element: a social judgment. A person truly qualifies as handicapped only when he or she is so labeled by others. Certain relatively severe types of impairments, such as blindness, deafness, absence or paralysis of arms or legs, or serious degrees of mental retardation or of mental illness, are nearly always considered handicaps in our society. Other impairments, such as the absence of a finger or a toe, mild mental retardation and emotional disturbance, color or night blindness, partial hearing loss, and many others, may or may not be considered handicaps. A person can be handicapped for one purpose and not for another; for example, the "six-hour mentally retarded child" is considered mentally retarded during the time he or she is in school but copes well and is considered "normal" outside the academic environment.

In a sense, "handicapped" is an artificial grouping created by the labeling process in our society. From the broad spectrum of human characteristics and capabilities certain traits have been singled out and called handicaps. The fine line between "handicapped" and "normal" has been arbitrarily drawn by the "normal" majority. Frequently, the various disabilities called "handicaps" have nothing in common except the label itself:

> Whatever characteristics such individuals may or may not have had in common prior to their classification, it is their involvement in the classification process that has generated the characteristics they all share—their social fate as members of a status category.

Moreover, a person whose condition need not be a substantial impediment may become "handicapped" if he or she is labeled and treated as "handicapped" by members of society. Educators and psychologists use the term "self-

fulfilling prophecy" to describe a process whereby persons assigned stigmatizing labels tend to conform to the expectations created by such labels. This effect may be magnified when, as in the case of handicapped persons, the label has practical and legal ramifications. Burgdorf and Burgdorf, *Santa Clara Lawyer*, at pp. 857-858.

APPENDIX II

The Declaration on the Rights of Disabled Persons

THE GENERAL ASSEMBLY

MINDFUL of the pledge made by Member States, under the Charter of the United Nations, to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development,

REAFFIRMING its faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the Charter,

RECALLING the principles of the Universal Declaration of Human Rights,[1] the International Covenants on Human Rights,[2] the Declaration on the Rights of the Child,[3] and the Declaration on the Rights of Mentally Retarded Persons,[4] as well as the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organization, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the United Nations Children's Fund and other organizations concerned,

RECALLING ALSO Economic and Social Council resolution 1921 (LVIII) of 6 May 1975 on prevention of disability and rehabilitation of disabled persons,

EMPHASIZING that the Declaration on Social Progress and Development[5] has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,

BEARING IN MIND the necessity of preventing physical and mental disabilities and of assisting disabled persons to develop their abilities in the most varied fields of activities and of promoting their integration as far as possible in normal life,

AWARE that certain countries, at their present stages of development, can devote only limited efforts to this end,

PROCLAIMS this Declaration on the Rights of Disabled Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

1. The term "disabled person" means any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of a deficiency, either congenital or not, in his or her physical or mental capabilities.

2. Disabled persons shall enjoy all the rights set forth in this Declaration. These rights shall be granted to all disabled persons without any exception whatsoever and without distinction or discrimination on the basis of race, color, sex, language, religion, political or other opinions, national or social origin, state of wealth, birth or any other situation applying either to the disabled person himself or herself or to his or her family.

3. Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever their origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.

4. Disabled persons have the same civil and political rights as other human beings; paragraph 7 of the Declaration on the Rights of Mentally Retarded Persons* applies to any possible limitation or suppression of those rights for mentally disabled persons.

5. Disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible.

6. Disabled persons have the right to medical, psychological, and functional treatment, including prosthetic and orthotic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum

**Paragraph 7 of the Declaration on the Rights of Mentally Retarded Persons states: "Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities."*

and will hasten the process of their social integration or reintegration.

7. Disabled persons have the right to economic and social security and to a decent level of living. They have the right, according to their capabilities, to secure and retain employment or to engage in a useful, productive and remunerative occupation and to join trade unions.

8. Disabled persons are entitled to have their special needs taken into consideration at all stages of economic and social planning.

9. Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subjected, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or by the improvement that he or she may derive therefrom. If the stay of a disabled person in a specialized establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.

10. Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature.

11. Disabled persons shall be able to avail themselves of qualified legal aid when such aid proves indispensable for the protection of their persons and property. If judicial proceedings are instituted against them, the legal procedure applied shall take their physical and mental condition fully into account.

12. Organizations of disabled persons may be usefully consulted in all matters regarding the rights of disabled persons.

13. Disabled persons, their families and communities shall be fully informed, by all appropriate means, of the rights contained in this Declaration.

The above is a resolution adopted by the United Nations General Assembly, December 9, 1975, on the report of its Social, Humanitarian and Cultural (Third) Committee.

REFERENCES

1. General Assembly resolution 217 A (III).
2. General Assembly resolution 2200 A (XXI), annex.
3. General Assembly resolution 1386 (XIV).
4. General Assembly resolution 2856 (XXVI).
5. General Assembly resolution 2542 (XXIV).

APPENDIX III

Federal agencies administering federal assistance are authorized to enforce compliance:

> 1. Administratively, by termination of or by refusal to grant or continue assistance after opportunity for a hearing and a finding on the record of noncompliance or,
>
> 2. By any other means authorized by law, i.e., granting agency may refer the matter to the Department of Justice for judicial action.

Before taking enforcement action, notice of failure to comply with the requirement must be given by the agency concerned and there must be a determination by the agency that compliance cannot be secured by voluntary means. Some effort must be devoted to attempts to secure voluntary compliance. The length of time involved and the nature of attempts to secure voluntary compliance will vary with such matters as the position taken by the recipient and the individual recipient's record. A federal agency affected by provisions similar to Sections 503 and 504 does not have unbridled discretion to pursue a source of negotiating voluntary compliance to the exclusion of any ultimate decision on whether to proceed through administrative hearing or to pursue other legal means in order to effect compliance. A federal court has held that where a recipient is unresponsive after a reasonable time has been allowed it to comply voluntarily, the federal agency concerned must proceed with enforcement by one of the five alternative means. Consistent failures by agencies to act constitute a dereliction of duty reviewable by the courts. (*Adams v. Richardson*, 480 F. 2d b 159, at p. 1183 (D.C. Cir. 1973)).

APPENDIX IV

Executive Order 11914
April 28, 1976

NONDISCRIMINATION WITH RESPECT TO THE HANDICAPPED IN FEDERALLY ASSISTED PROGRAMS

By virtue of the authority vested in me by the Constitution and statutes of the United States of America, including section 301 of title 3 of the United States Code, and as President of the United States, and in order to provide for consistent implementation within the Federal Government of section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794), it is hereby ordered as follows:

Section 1. The Secretary of Health, Education, and Welfare shall coordinate the implementation of section 504 of the Rehabilitation Act of 1973, as amended, hereinafter referred to as section 504, by all Federal departments and agencies empowered to extend Federal financial assistance to any program or activity. The Secretary shall establish standards for determining who are handicapped individuals and guidelines for determining what are discriminatory practices, within the meaning of section 504. The Secretary shall assist Federal departments and agencies to coordinate their programs and activities and shall consult with such departments and agencies, as necessary, so that consistent policies, practices, and procedures are adopted with respect to the enforcement of section 504.

Section 2. In order to implement the provisions of section 504, each Federal department and agency empowered to provide Federal financial assistance shall issue rules, regulations, and directives, consistent with the standards and procedures established by the Secretary of HEW.

Section 3. (a) Whenever the appropriate department or agency determines, upon all the information available to it, that any recipient of, or applicant for, Federal financial assistance is in noncompliance with the requirements adopted pursuant to this order, steps to secure voluntary compliance shall be carried out in accordance with standards and procedures established pursuant to this order.

(b) If voluntary compliance cannot be secured by informal means, compliance with section 504 may be effected by the suspension or termination of, or refusal to award or continue, Federal financial assistance or by other appropriate means authorized by law, in accordance with standards and procedures established pursuant to this order.

(c) No such suspension or termination of, or refusal to award or continue, Federal financial assistance shall become effective unless there has been an express finding, after opportunity for a hearing, of a failure by the recipient of, or applicant for, Federal financial assistance to comply with the requirements adopted pursuant to this order; however, such suspension or termination of, or refusal to award or continue, Federal financial assistance shall be limited in its effect to the particular program or activity or part thereof with respect to which there has been such a finding of noncompliance.

Section 4. Each Federal department and agency shall furnish the Secretary of Health, Education, and Welfare such reports and information as the Secretary requests and shall cooperate with the Secretary in the implementation of section 504.

Section 5. The Secretary of Health, Education, and Welfare may adopt rules and regulations and issue orders which he deems are necessary to carry out his responsibilities under this order. The Secretary shall ensure that such rules, regulations, and orders are not inconsistent with, or duplicative of, other Federal Government policies relating to the handicapped, including those policies adopted in accordance with sections 501, 502, and 503 of the Rehabilitation Act of 1973, as amended, or the Architectural Barriers Act of 1968 (42 U.S.C. 4151 et seq.).

Consumer advocacy groups believe that:

1. an economic impact statement or any statement dealing with the costs and benefits of Section 504 regulations should not in any way shape the substance of Section 504 regulations. Such statements, where required, should be treated as only informational. Section 504 establishes as a matter of federal law the duty of all recipients of federal aid not to discriminate on the basis of handicapping conditions. That law must be enforced and federal agencies must enforce it. Similarly, a recipient's claim of undue economic hardship in no way diminishes his obligation to comply with Section 504 or the Federal Government's obligation to enforce it. We believe that the duty not to discriminate imposed on recipients of federal aid by Section 504 is unqualified. Discrimination may be found in the failure to accommodate the special needs of the handicapped resulting in the handicapped being denied participation in the benefits of federally aided activity. Where it is a duty to accommodate results.

2. the regulations must condemn not only the failure to treat the handicapped like others (of, the concept of "color blind"), but also the failure to do so results in a denial of their right to participate in a program. We think that it is confusing to focus the analysis on the distinction between discrimination and affirmative action. In the area of the rights of the handicapped, as in the area of the non-English speaking, the duty not to discriminate may involve the duty to affirmatively accommodate the special needs of the handicapped. It is a serious mistake to confuse any "affirmative action" requirement (such as that in Section 503 of the RehabilitationAct), which does not depend upon a shoring of discrimination, with the duty to take whatever steps are necessary, affirmative or otherwise, as a remedy for proven discrimination. This principle applies in all education programs, health, social services, employment, and income maintenance.

3. architectural barriers is an issue which is not severable. It should be dealt with in each functional area. It should be discussed as part of the concept of "discrimination and the duty to accommodate" and ots cuts across all areas of HEW and other federal agency activity.

4. the individual is otherwise qualified if, after accommodation has been made so that opportunities are equalized, he or she is qualified to participate in a federally aided activity. If that phrase is not so construed, it negates most of the effect of Section 504. An example is the paraplegic for whom some special platform must be developed to enable him to reach certain production materials in a technical job. He is otherwise qualified, where he is technically qualified to do the work after the accommodation for his wheelchair is made. In areas other than employment, "otherwise qualified" means that one is eligible to participate in the program under the eligibility qualifications of applicable law.

APPENDIX VI

With respect to the employment rights of handicapped persons, the following chart* is a selective listing of State statutes:

Some states in which the disabled are covered under Fair Employment Practices Acts.

California	Nebraska
Connecticut	Nevada
Hawaii	Oregon
Maryland	Rhode Island
Montana	Wisconsin

Some states in which the disabled are covered under general civil rights statutes.

Iowa	New Jersey
Indiana	New Mexico
Maine	Pennsylvania
Minnesota	Washington

Some states which appear to have particularized statutes dealing with disabled persons, which may or may not cover employment activities.

California	South Carolina
District of Columbia	Texas
Florida	Vermont
North Carolina	West Virginia
Oklahoma	

*Excerpt from *Accent on Living* (Spring, 1976).

APPENDIX VII

This decision is reportedly the first one to rely on Section 504 as a basis for the holding:

Hairston v. Drosick
*No. 75-0691 CH (S.D. W.Va.)**

Trina Hairston is a spina bifida child who has a noticeable limp and incontinence of the bowels. School officials refused to place her in a regular classroom unless her mother would go to the school two or three times a day to attend to Trina. Additional alternatives to school attendance offered by the defendants were homebound instruction or placement in a special education class at a school for physically handicapped children.

Mrs. Hairston, however, was unable to attend to Trina at school because she had a baby at home to care for, her own mother was living in the household and was totally incapacitated, she had no driver's license or suitable transportation to the school, and her continued presence in the home was necessary because she took telephone orders for her husband, who makes his living by delivering loads of coal for heating homes.

The Hairstons, after unsuccessful attempts to secure Trina's admission to a regular first grade classroom, filed this suit in the United States District Court for the Southern District of West Virginia. In the suit, the Hairstons alleged that

*Excerpt from 1 AMICUS 6 (March 1976).

the exclusion of Trina from an educational program constituted a discrimination based on her handicap, in violation of Section 504 of the Rehabilitation Act of 1973 (29 U.S.C. Sec. 794) which prohibits discrimination against and denial of benefits to handicapped persons in any program or activity receiving federal financial assistance. Secondly, the Hairstons contended that Trina had been excluded from a regular public classroom without written notice and procedural safeguards in violation of the due process clause of the 14th Amendment to the United States Constitution.

The court determined that both of the plaintiff's contentions were correct, and ordered that Trina Hairston be admitted immediately to a regular public classroom. Judge K. K. Hall, who presided in the case, also ordered that any attempt to exclude her be in accord with due process of law, and that any exclusion be reviewed by the court itself prior to such action.

Section 504 Used As Basis

Hairston v. Drosick is significant because the court concluded that the plaintiff's exclusion from a regular classroom violated Section 504 of the Rehabilitation Act of 1973 which provides that:

"No otherwise qualified handicapped individual in the United States, as defined in Section 706(c) of this title, shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."

Although the U.S. Department of Health, Education, and Welfare was to have issued regulations to implement Section 504, no such regulations have yet been promulgated. Judge Hall, however, recognized that reliance could be placed directly on the statute.

"To deny a handicapped child access to a regular public school classroom in receipt of federal financial assistace without compelling educational justification constitutes discrimination and a denial of the benefits of such program in violation of the statute," Judge Hall said in his order of January 14, 1976. "School officials must make every effort to include such children within the regular public classroom situation," he wrote, *"even at great expense to the school system."* (Emphasis added.)

Socialization Process Imperative

The court also found alternative placement of handicapped children able to function adequately in a regular classroom unacceptable and a great disservice to these children. In his order, Judge Hall remarked, "A child's chance in this society is through the educational process. A major goal of the educational process is the socialization process that takes place in the regular classroom, with the resulting capacity to interact in a social way with one's peers. It is, therefore, imperative that every child receive an education with his or her peers insofar as it is at all possible. The conclusion is further enforced by the critical importance of education in this society. . . . It is an educational fact that the maximum benefits to a child are received by placement in as norman environment as possible."

APPENDIX VIII

Friedman, an attorney confined to a wheelchair, attempted to enter five county buildings in Cleveland, four housing courtrooms. He could not enter any of them without assistance. He filed a class action suit in the Court of Common Pleas for the County of Cuyahoga, seeking a declaratory judgment as to right to access and injunctive relief. Since the buildings were not covered by the Ohio architectural barriers statute, the legal action was based on rights guaranteed by the United States and Ohio Constitutions.

The plaintiff argued that the acts of the county commissioners in maintaining barrier-laden buildings amounted to: denial of access to the courts, denial of access to a seat of government in derrogation of the right of free petition, denial of right to travel and freedom of movement and denial of equal protection in that the barriers unjustifiably limited equal

employment opportunity. These infringements on constitutional rights, Friedman asserted, placed a burden of affirmative action on the county commissioners to provide access to all handicapped citizens.

The lawsuit was resolved by agreement of the county commissioners to install ramps and insure accessibility in all existing county-owned buildings. The judicially approved consent decree also provided that all county buildings constructed in the future must conform to accessibility standards.

APPENDIX IX

Excerpt from:
Burgdorf and Burgdorf, Vol. 15,
Santa Clara Lawyer, pp. 899-910.

The fourteenth amendment forbids a state to deny to any person within its jurisdiction the equal protection of the laws. If a state has become significantly involved in the unequal treatment of its citizens, the discriminatory treatment—whether legislative, administrative, or judicial—may be challenged under the equal protection clause. State activity is subject to judicial nullification where it "individuously" singles out one particular group from among those "similarly situated."

On the other hand, nearly all statutes and regulations employ classifications. Under an equal protection analysis, legislatively or administratively imposed distinctions will be examined in light of their overall purpose. A classification is "under-inclusive" when it fails to include all those who are similarly situated with respect to the general purpose of the law. An "over-inclusive" classification affects a wider range of persons than those whom the particular law may legitimately reach. Some laws contain elements of both under- and over-inclusiveness; but the classification cannot be characterized until *after* the purpose of the law has been identified.

Over the years, the Supreme Court has used various standards for reviewing state acts which discriminate among classes of citizens. During the Warren era, the burden imposed upon the government to justify such laws depended on which of the two levels of scrutiny the Court employed. The "strict scrutiny" test upheld a classification only if the state convincingly demonstrated that it was necessary to promote a "compelling" governmental interest. In such cases, the state was required to rebut the presumption that its interest could be furthered by a more carefully tailored classification or by some less drastic alternative. The rigorous level of scrutiny would be invoked when legislation or some other form of state action (1) contained classifications which were inherently "suspect," such as those based on race or nationality, or (2) affected a "fundamental right" either expressly or impliedly guaranteed by the constitution, such as the right to vote or to have offspring.

A second, less demanding level of judicial review was used when neither condition for strict scrutiny was present. This alternative standard, known as the "rational basis" test, upheld the classification if it was reasonably related to a legitimate governmental objective. While the burden was upon the state to demonstrate a compelling interest in strict scrutiny cases, statutory validity was presumed under the rational basis test.

When it applied "strict scrutiny," the Court generally struck down the challenged state action. Until very recently, use of the rational basis test meant minimal scrutiny and was an almost sure tipoff that the Court would uphold the classification against an equal protection attack.

This two-tiered approach has been criticized as too rigid and mechanistic. Since 1971 the Burger Court has shown signs of opting for new, more flexible standards of review. Strict scrutiny, however, continues to be invoked where states adopt classifications well established as "suspect." During the past four years, the Court has added alienage to the "suspect" group, while broadly implying that women and illegitimate children merit similar consideration.

SELECTED BIBLIOGRAPHY

1. Achtenberg, " 'Crips,' United to Enforce Symbolic Laws; Legal Aid for the Disabled: An Overview," Vol. 4, *University of San Fernando Valley Law Review*, p. 161 (Fall, 1975).
2. Adler and Gorman, *The American Testament*, (1975).
3. Architectural and Transportation Barriers Compliance Board, First Report to the United States Congress (November, 1974).
4. Brakel and Rock, *The Mentally Disabled and the Law*, (Revised Edition, 1971).
5. Burgdorf and Burgdorf, "A History of Unequal Treatment: The Qualifications of Handicapped Persons as a 'Suspect Class' under the Equal Protection Clause," Vol. 15. *Santa Clara Lawyer*, pp. 855-910 (Summer, 1975).
6. Comptroller General of the United States, "Employment Opportunities In the Federal Government for the Physically Handicapped," (Report to Congress, September 16, 1974).
7. Comptroller General of the United States, "Further Action Needed to Make All Public Buildings Accessible to the Physically Handicapped," (Report to Congress, July 15, 1975).
8. Diamond, "Winning a Bill of Rights for the Disabled," Vol. 3, *Student Lawyer*, p. 20, (October, 1974).
9. Elmes and Herrmann, *Handbook of the Legal Rights of Handicapped People* (Federal, District of Columbia, Maryland and Virginia Laws), President's Committee on the Employment of the Handicapped, 1976).
10. Farber, "The Handicapped Plead for Entrace—Will Anyone Answer"?, Vol. 64, *Kentucky Law Review*, pp.99-113.
11. Final Report of Wisconsin's Task Force on Problems of People with Physical Handicaps, (July 19, 1974).
12. Handel, "The Role of the Advocate in Securing the Handicapped Child's Right to an Effective Minimal Education," Vol. 36, *Ohio State Law Journal*, pp. 349-375.
13. Klein, "Background Paper on the Civil Rights of the Mentally Ill," (submitted by Staff Attorney of the Washington, D.C., Mental Health Law Project).
14. Laski, "Civil Rights Victories for the Handicapped—I and II," Vol. I, *The Social and Rehabilitation Record*, pp. 15-20, 25032, (May and June, 1974).
15. The National Center for the Law and Handicapped (South Bend, Indiana), "Legal Rights of the Handicapped." (R. Burgdorf, Jr.)
16. Note, "Abroad in the Land: Legal Strategies to Effectuate the Rights of the Physically Disabled," Vol. 61, *Georgetown Law Journal*, p. 1501. (July, 1973).
17. Presient's Committee on Mental Retardation (1974), *Compendium of Law Suits Establishing the Legal Right of Mentally Retarded Citizens*, (Edward Lynch).
18. Raggio, *et al*, "Equal Access to Public Transportation: The Disabled and the Elderly," (September, 1975).
19. tenBroek, "The Right to Live in the World: The Disabled in the Law of Torts," Vol. 54, *California Law Review*, p 84 (1966).
20. *United States Civil Rights Commission Report, The Federal Civil Rights Enforcement Effort*, 1974, Vol. VI, "To Extend Federally Financed Assistance," (Nov., 1975).
21. *United States Civil Rights Commission Report*, "The Voting Rights Act: Ten Years After," (January, 1975).
22. United States Civil Service Commission, "Employment of Handicapped Individuals Including Disabled Veterans in the Federal Government," (June 30, 1975).
23. Wald, "The Legal Rights of People with Mental Disabilities in the Community: A Plea for Laissez Faire," *Legal Rights of the Mentally Handicaapped* at p. 1033 (1973).

Civil Rights—Responsible Legal Action and Advocacy

President Wilson said that it was not enough to declare that men and women have rights; it is necessary to take action to protect those rights. In fact, it may be said that a right not recognized or enforced amounts to no right initially. Rights, liberties and attached responsibilities ineluctably compel action. Action is picking and charting policies. Action converts into politics and political actions. Persons with or without physical and mental disabilities are the bits and pieces of the body politic which is the corporeal body of the State.

Political action is almost an obligation or at least a natural concommitant to the achievement of the full recognition of rights, the full recognition of personhood.

Full civil rights, full personal dignity and full human happiness for all Americans who are physically or mentally disabled have been declared goals not only of the White House Conference but most significantly of the leaders whose responsibility and obligation it will be to take necessary and appropriate actions to enforce those rights.

Significantly, President Jimmy Carter has publicly committed himself to the proposition that disabled people deserve to control and shape their own lives. Furthermore, he has pledged to ensure that "disabled citizens have the right and the opportunity to function independently and creatively in our society, rather than to be segregated from (it)" Of course it remains to be seen how and whether these goals will be attained.

Lawyers and Legal Advocacy

The second half of the 1970's promises to accelerate and to broaden the efforts to pursue litigations; and legislative and administrative remedies to secure the rights of Handicapped Americans.

Legal advocates—lawyers, paralegals, and non-lawyer advocates—embrace handicapped persons themselves and groups such as the National Center for Law and the Handicapped (South Bend, Indiana), National Center for Law and the Deaf (Washington, D.C.), Public Interest Law Center of Philadelphia (Pennsylvania), Mainstream (Washington, D.C.), Developmental Disabilities Rights Center (Baltimore, Maryland), Disability Rights Center (Washington, D.C.), Western Law Center (Los Angeles, Calif.), Mental Health Law Project (Washington, D.C.), and others throughout the country.* A growing number of attorneys in private practice or associated with Legal Services Corporation is engaged in legal advocacy activities on behalf of disabled persons. Efforts are continuing to establish at least an informal network of communications among members of the legal community on the problems of handicapped persons.

HEW Proposes Regulations for Section 504*

Proposed regulations to implement Section 504 of the Rehabilitation Act of 1973 within the Department of Health, Education and Welfare, were issued July 16, 1976.

Section 504 provides that "no otherwise qualified handicapped individual in the United States, . . . shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."

The proposed regulations follow a Notice of Intent and draft regulations published in the *Federal Register* May 17, 1976, which indicated HEW plans to implement Section 504. This Notice resulted in written comments submitted to the Office of Civil Rights (OCR) concerning the draft regulations and an attached statement of the estimated economic and inflationary impact of the draft proposal.

"The July 16 proposals cover and define nondiscrimination in the areas of employment practices, architectural accessibility, education, health, welfare, and social services. Handicapped individuals entitled to the protections of the proposed regulations include eligible or qualified employees or beneficiaries of HEW-assisted programs who have 'a mental or physical impairment which substantially limits one or more major life activities' (e.g., caring for one's self, walking, speaking), or who have a history of such impairments, or who are regarded (by service

*Legal advocacy groups are being established under the provisions of the Developmental Disabilities Assistance and Bill of Rights Act of 1975.

**Amicus* (National Center for Law and the Handicapped), September 1976 at pp. 4–5.

providers or others) as having such impairments."*

"The United States District Court for the District of Columbia has ruled that the Secretary of the U. S. Department of Health, Education, and Welfare is required to promulgate regulations effectuating Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. Section 794, as amended. *Cherry v. Mathews,* No. 76–255 (D.D.C., July 19, 1976). The court has retained jurisdiction over the matter 'to assure that no further unreasonable delays' affect the issuance of the regulations.** The Department had agreed that since the section contained no language requiring rule making, the Department had no duty to issue regulations. (Such language had appeared in the Senate Report but did not survive enactment.) The court, however, found an underlying Congressional intent that the section, although not self-executing, be nonetheless swiftly implemented by the issuance of regulations by the Secretary."*

The May 17 Notice sought comments on three specific issues which HEW felt should be considered apart from the draft regulations themselves. First was the issue of whether or not homosexuals, alcoholics, and drug addicts should be considered as groups to be protected under Section 504.

According to the proposed regulations, homosexuals will not be considered "handicapped." However, drug addiction was found to be within the statutory definition of "handicap" as set forth in the Rehabilitation Act of 1973.

The second issue concerned the degree of specificity necessary in the regulations to "provide adequate and accurate guidance to the public but, at the same time, to allow sufficient flexibility to foster prompt cooperation and compliance."

HEW has decided to continue with its specific and detailed mandates, as opposed to more general statement which would delegate discretion to recipients. This decision was made on the basis that most comments favored detailed regulations as necessary to apprise beneficiaries of their rights, and to inform recipients of their responsibilities under Section 504.

The third issue concerned what HEW terms "balancing competing equities," that is, carefully "assessing the overall impact of a particular requirement both on the persons protected by the statute, and those regulated by it."

The Department of HEW has concluded, despite numerous comments that the statute is absolute and contains no exception designed to allow such discretion, that its position on this matter as stated in the May 17 draft regulations was correct.

The Department, however, specifically asserts its commitment to the principle that "cost or difficulty are appropriate considerations, not in determining what constitutes discrimination, but in fashioning a remedy if a recipient has been found to be discriminating."

Attitudinal changes in the perception by the professional members of the legal justice system of the United States of handicapped persons will support the general recognition as contributing parts of the national community. The American Bar Association in 1973, established an interdisciplinary body (the Commission on Mental Disability) "to develop and implement programs designed to promote needed reforms in the nation's mental disability system. The Commission believes that clients of the mental disability system and other mentally disabled individuals will achieve full enjoyment of their legal rights only when members of the bar, responsible government officials, service providers, lay advocates, and consumers understand and are equipped to implement these rights on a day-to-day, case-by-case basis."*

At its 1976 annual meeting in Atlanta, Georgia, the American Bar Association (ABA) House of Delegates resolved to support vigorous enforcement of legislation to ensure access to public buildings and transportation services for the physically handicapped.*

The ABA Section of Individual Rights and Responsibilities initiated the resolution.

Under the resolution the ABA authorized its president, or his designee to testify before governmental bodies in support of federal, state, and local legislation, as well as policies and executive directives designed to ensure ready and effective accessibility.

**Mental Disability Law Reporter* (ABA Commission on the Mentally Disabled), September-October, 1976 at p. 141.

**On January 19, 1977, the District Court issued an injunction forbidding any further delay in issuing regulations. No further action by the Secretary of HEW to publish regulations had been taken at the time this paper was written.

**Mental Disability Law Reporter,* November-December, 1976, p. 199.

**Mental Disability Law Reporter,* July-August, 1976, p. 5.

**Amicus,* September 1976 pp. 3–4; Charles Goldman, Report to the American Bar Association House of Delegates from Section of Individual Rights and Responsibilities.

The ABA further resolved to ensure that its functions be held in barrier-free environments in the future, thereby serving as an example for other groups.

The Section's report on governmental action is critical of federal, state and local mandates requiring accessible design in government funded building and transit programs which result in bureaucratic inaction. According to the report, the power of legislative directives is weakened without the sanctions necessary for enforcement.

The physically handicapped, the report continues, are barred from participating in the normal functions of society. Obstacles such as street curbs, buildings without ramps, inaccessible elevators, narrow aisles and doorways, and inadequate toilet facilities and telephones often prevent the handicapped from utilizing public buildings and transportation. Therefore, they are restrained from coming to the seat of government to petition Congress, from transacting business, or obtaining government services; they cannot vote, attend public schools, conduct business, or become independent or self-supporting.

Although the federal and state governments have all, in varying degrees, taken steps to remove architectural barriers, the report points out that, "most State laws do not establish a special body to coordinate enforcement of, and compliance to, standards. Instead the States commonly leave such compliance responsibilities to State and local agencies charged with other duties, such as the fire marshall."

Although in the past decade there has been significant federal legislation, such as the Architectural Barriers Act of 1968, the Urban Mass Transportation Act of 1964, and Section 504 of the Rehabilitation Act of 1973, the report states that the statutes have generally been regarded as suggestive, not directive, and therefore, inadequately enforced.

The Section's report also notes that allegations as to the cost of barrier-free construction have been exaggerated. A July 15, 1975, report by the Comptroller General entitled "Further Action Necessary to Make Public Buildings Accessible," concludes that when barriers are eliminated in the initial design, the cost is negligible, and when barriers are eliminated in existing construction, the cost is still comparatively minor.

Architectural Accessibility*

On October 18, 1976, then President Ford signed into law Public Law 94–541, which amends the Architectural Barriers Act of 1968, pertaining to barrier-free design in federal buildings and facilities.

The purpose of the amendments is to impose what one Congressional sponsor called "a clear statutory mandate that the federal agencies named in the act insure that public buildings are made accessible to the physically handicapped."

Specifically, the language of the new law states more forcefully and stringently than the old Architectural Barriers Act the Federal government's obligation to accessibility. Where the old law provided that the Administrator of General Services and various cabinet officers were merely "authorized to prescribe" standards for accessibility, the new law directs that they "shall prescribe" such standards, and that such standards shall be adequate to insure wherever possible" that handicapped persons will have access to, and use of, such buildings.

The new law also makes it clear that the buildings of the U.S. Postal Service are covered by the federal architectural barriers laws.

Additionally, the law requires annual reports to Congress by the General Services Administration on the status of federal activities related to the Architectural Barriers Act. It also imposes on the agencies charged with enforcing the act the obligation to conduct a system of continuing surveys to insure compliance.

Included in the Federal Tax Reform Act of 1976 is a provision granting a deduction for the cost of removing architectural and transportation barriers for handicapped and elderly persons.

The new section of the tax code, sponsored by Senators Dole and Mondale, provides an elective current deduction for the removal of architectural and transportation barriers to handicapped (including deaf and blind persons) and elderly persons (age 65 or over) in any facility or public transportation vehicle owned or leased for use in a trade or business. Deductions are limited to $25,000 for a taxpayer for any taxable year.

To qualify for the deduction, the barrier removal must satisfy the standards of the Secretary of the Treasury. In cooperation with the Architectural and Transportation Barriers Compliance Board, the Secretary is required to

*_Amicus_, December 1976 at pp. 2, 10.

establish those standards within 180 days after the Tax Reform Act became law.

The provision for the deduction applies to taxable years beginning after December 31, 1976, and ending before January 1, 1980. See Section 1323 of the Tax Reform Act of 1976 and Section 190 of the Internal Revenue Code.

In an important development concerning accessibility of the Washington, D.C. Metro subway system, the U.S. District Court for the District of Columbia has refused to modify the requirements of its October 23rd, 1973 injunction.

At the same time, however, Judge William B. Jones indicated that resolution of this case, *Washington Urban League, Inc., et al. v. Washington Metropolitan Area Transit Authority, Inc.*, may possibly now be the responsibility of the Architectural and Transportation Barriers Compliance Board (A&TBCB).

The latest action by the court taken August 31, 1976, resulted from efforts by disabled plaintiffs in the case to seek clarification of the court's 1973 order with regard to "the nature of the facilities which (the transit authority) must install and make operational before it would be permitted . . . to operate commercially in the Gallery Place stations."

The Gallery Place stations are segments of the transit system which, in July, 1975, Judge Wm. Jones refused to permit to open because of inaccessibility. Prior to the plaintiffs' motion for clarification, a group of Washington, D.C. businessmen known as the National Capital Downtown Committee, Inc. (or Downtown Progress) intervened in the case as parties and asked the court to permit operation of the Gallery Place station.

In response to the action by the disabled plaintiffs and the Washington, D.C. businessmen, Judge Jones requested *amicus curiae* briefs from the General Services Administration, the A&TBCB, and the District of Columbia Government. After consideration of the briefs and arguments of the parties, the court rejected the contention of the businessmen that the Gallery Place stations should be permitted to open despite the fact that the facilities still fail to comply with the Architectural Barriers Act of 1968.

In their arguments, the businessmen alleged that ". . . the number of non-ambulatory handicapped who would use the station is minimal and certainly insufficient to close its use to the entire public, including the ambulatory handicapped . . . . The injunction helps no one, and harms everyone."

Judge Jones, however, held that "the inconvenience occurring to the public from the closing of Gallery Place is minimal." He pointed out that there was another station "a mere two blocks" from Gallery Place and that the downtown area was being served effectively "albeit with slight inconvenience to certain persons." More importantly, Judge Jones affirmed, was the court's opinion that the danger that the transit authorities would in the future fail to comply with the Architectural Barriers Act continued to be "substantial."

In the course of his decision, Judge Jones also took the opportunity to make a significant comment interpreting the meaning of the Architectural Barriers Act:

> Plaintiff-intervenors' argument that a building, which has been designed and constructed for accessibility, but incapable of use by handicapped persons, does not violate the Act, effectively stands the Act on its head. No matter how 'simple' and 'straightforward' the Act was intended to be, it was also intended to insure 'ready access to, *and use of*' defendant's building and structure. If the statute is not to be bereft of its very purpose, those words must clearly mean that the required facilities for the handicapped be operative, not merely in the process of installation.

On December 14, 1976, the Administrator of the General Services Administration (GSA) granted a temporary waiver under the 1968 Act to Metro allowing the opening of the Gallery Place Station until July 1, 1977. Subsequently, the plaintiffs challenged the validity of the granting of the waiver and sought to make GSA a party to the main suit. This is still pending before the court.

Transportation Accessibility*

On October 18, the Urban Transportation Administration (UMTA) announced further regulations to carry out the federal statutory requirements to bring about accessible transportation services for disabled persons.

The new regulations, entitled "Completion of Transit Bus Requirements," are intended to "complete and clarify" portions of the April 30,

**Amicus*, December 1976 at p. 2.

1976 accessibility regulations and also effectuate the August 2 UMTA Policy Statement.

The April 30 final regulations mandated the manufacture of wheelchair level change devices to be used at the option of transit systems, and an eight inch step riser height requirement for transit buses. The August 2 Policy Statement announced the intention to specify a February 15, 1977 effective date for those requirements, and mandated a 24 inch floor height requirement.**

Disenfranchisement of the Mentally Handicapped Citizen*

Voting is the symbol of citizenship. Blacks, women and youth have measured progress toward equality by their increased access to the ballot box. It is not therefore surprising that many mentally retarded persons and residents of mental institutions are not permitted to vote in Presidential elections. Like other trappings of citizenship, this too is denied them by a variety of barriers. Many states flatly prohibit "idiots," "insane persons," "persons of unsound mind," or "the feebleminded" from voting. These terms are rarely defined by the legislatures—if indeed they are capable of definition—and their application is left to the discretion of local registrars.

Other states attempt to provide an objective criterion by denying the franchise only to those who have been adjudicated incompetent or who are under guardianship. This determination is not based on an evaluation of an individual's mental condition; rather, the responsible election official need only ascertain the existence of a valid court order. Yet even this apparently neutral standard is problematical because it presumes the fairness and accuracy of judicial proceedings to determine competency or to appoint guardians—a process which is, in fact, terribly flawed in many states. Moreover, such a standard relates not to a person's ability to vote but to his capacity to cope with various other more complicated situations, such as management of household or money—none of them having to do with knowing who is running for President.

Still other states bar any institutionalized person from voting, equating commitment with incompetency—the same fiction historically used to explain why institutionalized persons had no legal rights at all. A double-barrelled rationale claims that the institutionalized (therefore incompetent) resident is under the "implied" guardianship of the state, and thus ineligible to vote.

Even when such obstacles are circumvented, persons in institutions may be told that they cannot vote at an accessible polling place because they are not legitimate residents of the county in which the institution sits. In many states which reserve absentee ballots for voters who will be out of state on Election Day, a person institutionalized far from his original residence becomes, perforce, a non-voter.

The Supreme Court has described the right to vote as the "essence of a democratic society" and has severely circumscribed the limitations that a state may constitutionally impose upon voting. A state must justify any voting restrictions by demonstrating some "compelling state interest" that overrides the individual's personal interest in voting, and the manner in which the state achieves this compelling interest must be precisely limited to accomplish only that purpose and nothing more.

The clearest application of these principles has occurred in the Court's series of "reapportionment" cases, where state legislatures gerrymandered districts in order to reduce the influence of black voters, which resulted in the pronouncement, "one person, one vote." A 1966 decision held unconstitutional a state's requirement that a poll tax be paid as a prerequisite to voting on the grounds that it "individually discriminated" against poor persons.

The Supreme Court has not yet had occasion to apply these strict standards to a typical state restriction on the voting rights of mentally retarded or institutionalized people, but such a challenge is likely. The court's closest consideration of the problem came in 1959, when a provision that all voters be able "to read and write any section" of a state constitution "in the English language" was challenged by black voters. The court upheld the law because on its face it seemed to apply to all persons. However, the court warned that if a literacy test were used

---

***Disabled in Action of Pennsylvania, Inc., et al. v. Coleman, et al.*, filed on June 17, 1976 is now pending in the Federal District Court for the Eastern District of Pennsylvania at Philadelphia. It is a lawsuit on behalf of handicapped and elderly persons to require federally funded transportation programs to implement the Transbus vehicle in their operations. Transbus is the prototype low-floor, wide-door, ramped bus which has been under development by the Urban Mass Transportation Administration for 9 years.

*Robert Plotkin, *Mental Health Law Project, Summary of Activities*, Fall 1976, pp. 1, 11.

to discriminate against a particular class, the result might be different.

Since that time, Congress in the Voting Rights Act has forbidden the use of "tests" or "devices" that discriminate on the basis of a voter's literacy or educational achievements. While the act was designed to eliminate racially motivated limitations, there is every reason to believe that it also forbids "tests" or devices to measure a retarded person's I.Q. The act stands as a heavy presumption against intelligence as a criterion upon which anyone's right to vote may be conditioned.

Not all states prevent mentally retarded or mentally ill persons from voting and, in fact, in some, legislation specifically preserves their voting rights. But still they do not vote. Sadly, treatment and rehabilitation professionals, institutional staff, parents and guardians make little effort to help clients and relatives register. Throughout the country there are institutions and community centers, full of legally eligible voters, where not one is registered because no one has pointed out their rights or initiated a registration drive. Well-meaning parents, otherwise zealous advocates for their offspring, cannot imagine "little" 30-year-old Johnny voting for a President.

Concerned professionals have organized voter-registration drives in several areas. The Suffolk (N.Y.) Developmental Center registered some 250 of its retarded clients in 1974; recent lawsuits in New Jersey and Massachusetts have permitted numerous institutionalized retarded persons to register. The Great Oaks Center, in Montgomery County, Maryland embarked upon a drive to register voters for the 1976 Presidential elections; of 250 eligible residents, 71 registered. (Many of those who declined to register gave as a reason their disenchantment with politicians in general—a familiar refrain on the "outside.") These drives are easy to undertake. They require research into local voting laws and procedures, and perhaps direct contact with the registrar's office to anticipate and resolve any potential problems. Education programs are helpful, like those conducted by the League of Women Voters at nursing homes and for the general public, to familiarize the voters with the election process and the voting machines, and local candidates could be invited to visit institutions to meet these voters.

To be sure, the right to vote does not put food on the table or a roof over one's head. But, as other minorities have demonstrated, denial of that right is a label of second-class citizenship too easily and too often extended to education, employment and housing. Deprivation of suffrage, in other words, signifies society's attitude toward the mentally disabled. It is the attitude with its resulting neglect and discrimination, which must be cast aside.

SELECTED BIBLIOGRAPHY

Grateful appreciation is expressed for the use of excerpts (without quotation marks) from the following sources:

1. Jeannine Villing, *Amicus* (National Center for Law and the Handicapped, Editor), September and December, 1976.
2. Charles Goldman, Report to the House of Delegates of the American Bar Association, Section of Individual Rights and Responsibilities (August, 1976).
3. *Mental Disability Law Reporter* (American Bar Association, Commission on the Mentally Disabled), July-August, September-October, November-December, 1976.
4. Robert Plotkin, "Too 'CRAZY' to Vote? Disenfranchisement of the Mentally Handicapped Citizen," *Mental Health Law Project, Summary of Activities,* Fall, 1976.

UNIQUE PROBLEMS OF HANDICAPPED MINORITIES

Awareness Paper Prepared By

Ron Wakabayashi, Chairperson
Asian Rehabilitation Services, Inc.
Los Angeles, California

George E. Ayers, Ph.D.
Vice President
Metropolitan State University
St. Paul, Minnesota

Orlando A. Rivera
Associate Vice President for Academic Affairs
University of Utah
Salt Lake City, Utah

Linda Quintana Saylor
Assistant Professor of Nursing
University of Utah
Salt Lake City, Utah

Joseph L. Stewart, Ph.D.
Indian Health Service
Albuquerque, New Mexico

TABLE OF CONTENTS

SECTION I

UNIQUE PROBLEMS OF HANDICAPPED ASIAN AMERICANS

Page

Introduction 429

Asian Americans 429

Service Delivery Barriers 430

Population Identification 431

Target Charcteristics 432

Summary 432

Bibliography 432

SECTION II

UNIQUE PROBLEMS OF HANDICAPPED BLACK AMERICANS

Introduction 432

Societal Attitudes 434

Attitudes of Professionals 435

Communication 436

Attitudes of Handicapped Black Americans 437

Summary 438

References 438

ACKNOWLEDGMENT

The White House Conference on Handicapped Individuals wishes to thank the following individuals who have contributed significantly to this document:

Dr. Edward Wm. Hawthorne, MD., Ph.D.
Dean, The Graduate School For Arts And Sciences
Howard University, Washington, D.C.

William Carlile, MD.
Senior Clinician In Pediatrics
Indian Health Services
Albuquerqe, New Mexico

SECTION III

UNIQUE PROBLEMS OF HANDICAPPED NATIVE AMERICANS

Introduction 438

Discussion of the Problem 438

Behavioral-Emotional Disorders 440

Communication Disorders: Otitis Media 442

Addendum 442

Historical Perspective 443

State of the Art 443

Bibliography 444

SECTION IV

UNIQUE PROBLEMS OF HANDICAPPED INDIVIDUALS WITH SPANISH SURNAMES

Introduction 444

Historical Perspectives 445

Cultural Characteristics 445

Cultural Shock and Social Services 446

Recommendations 447

Bibliography 448

INTRODUCTION

While it is true that handicapped individuals who are members of racial and ethnic minorities suffer the same indignities as other handicapped individuals, there are special and unique problems that these individuals face because of the lack of awareness of cultural differences. For example, pervasive discrimination and segregation in employment, education, and housing, have resulted in the continuing exclusion of great numbers of ethnic minorities from the benefits of economic progress. In addition, prejudice and racial discrimination continue to exclude a great number of these individuals from full participation in all aspects of society.

Handicapped people and particularly ethnic minorities who are handicapped have two basic psychological needs. One is the need for self-esteem, i.e., for high self-evaluation, and the second is the need for social status, i.e., high evaluation by others. As a result of these two factors, people have a tendency to develop according to what we expect of them. The self-image of the handicapped minority seeking help is deeply affected by the manner in which he/she is treated, the goals the person providing assistance for him/her, and the expectations he has of him/her. The prejudices these individuals providing assistance may harbor about the ethnic minority will damage the success of their work with them. Ethnic minorities must be viewed as the "whole" man and the prejudices and misconceptions which are prevalent in our society must be eradicated.

All these factors tend to place handicapped minorities at increased disadvantages compared to other handicapped individuals. This paper discusses the unique problems of the following ethnic minority groups in our society; Asian Americans, Black Americans, Native Americans, and those with Spanish Surnames. It is, therefore, divided into four sections which discuss the problems faced by handicapped ethnic minorities from each of the above-mentioned populations.

SECTION I
UNIQUE PROBLEMS OF HANDICAPPED ASIAN AMERICANS

INTRODUCTION

Physical and mental disabilities affect Asian Americans in a manner not unlike other citizens and residents of the nation. Handicaps of every variety are experienced within the population. Asian Americans are, however, differentiated by their particular cultural backgrounds and history, as well as their degree of participation in the service delivery systems that have traditionally responded to the needs of the handicapped. This paper shall attempt to provide highlights of the major distinguishing factors of the Asian American handicapped populations as compared to other minority populations.

The presentation of any topic related to Asian Americans is intrinsically complex and incomplete. The designation, Asian American, has a current and evolving definition that responds to the dynamic condition of numerous ethnic communities that modify the definition. In California, where a third of the total population of Asian Americans residing on the mainland United States concentrate, the term may include fifteen or more culturally, ethnically and linguistically distinct communities. The problem of adequate presentation is further complicated by the inadequacy of existing data collection and retrieval systems, which fail to segregate or collect data on Asian American populations. This situation is a significant symptom of the Asian American dilemma, as the invisibility of the population may typify the degree of interest and concern for serving this population.

ASIAN AMERICANS

The multi-ethnic term, Asian American, is generally inclusive of populations from Asian nations. More recently, practice has included Pacific Island populations such as Hawaiian, Tongan, Samoan and Guamanian. While the initial rationale for these populations to join together reflected an objective to achieve greater visibility, the term, too often, has merely been a substitution for persons, who could not be designated as White, Black, Native American or Spanish Surname. Asian Americans share a number of common experiences. The majority population has historically and currently viewed them as a monolithic group. This tendency is

manifested in the muddled transference of particular stereotypes for a particular ethnic group inappropriately from one ethnic group to another. Stereotypes or images of more visible Asian American Groups, such as the Chinese or Japanese, are very often mixed and undifferentiated. Therefore, Asian Americans are perhaps, the least acknowledged of the national minorities.

The approximate number of two million Asian Americans in this country represent a hundred year plus history of immigration and resettlement in the United States. Early Chinese and Japanese immigrants came to American shores, arriving with the belief that America afforded them the opportunity to better their lot. The early experience contains a theme of exploitation and maltreatment, which included exclusion from citizenship, exclusion from land ownership, exclusion from particular employment, segregation in schools. The discrimination against early Asian immigrants was codified in over 600 laws that were directly focused to discriminate against them. In this hostile environment early colonies of Asian Americans began developing internal devices to provide for the welfare of the group. Based upon family, church, prefectural or fraternal relationships, the ethnic communities developed alternative institutions that paralleled the functions of existing majority culture institutions. The development of these institutional structures as a basis of survival significantly affects the structure of service delivery systems that would, today, seek to outreach to Asian Americans. These institutions reflected the mistrust that the communities developed for public institutions.

Succeeding generations and subsequent Asian immigrant waves, such as the Filipino and Korean groups, inherited this experience of mistrust. The incarceration of 110,000 Japanese Americans, most of who were citizens of the United States, during the Second World War greatly reinforced a condition where Asian Americans subtly accepted and recognized a status as second class citizens. The analogy of an unwelcome guest residing within the domain of a hostile host, reflected the situation of Asian Americans. Consequently, Asian communities adopted a strategy of accommodation toward the dominant host culture.

The effect of an attitude of accommodation toward the host culture created a mixed reaction. The overtly negative stereotypes of the communities became modified to the extent that Asian Americans became viewed as a "model minority." Accommodation developed into a community characteristic that sought to be as unobtrusive as possible, and in that manner avoiding the displeasure of the host culture. In effect, much of the energy of Asian American communities was directed toward becoming non-threatening and invisible. One aspect of this effort to achieve invisibility is represented in a dominant concern within the ethnic communities to shed themselves of as many vestiges of racial, ethnic, cultural or social differences as possible. This phenomenon eventually carries over to a developed characteristic behavior that promoted the active denial of deviance within the ethnic community. Acknowledgement of deviance or social problems in this setting would endanger the invisibility that the community sought, and would detract from the model minority image that was presented. The Operation of these dynamics in the ethnic community coupled with a generalized mistrust of public service delivery systems, operate to impair any realistic visibility of human needs outside of the ethnic community.

Within the ethnic communities, the alternative institutions that existed, operated on relatively meager resources. From a cultural value perspective, consumers of these services would be bound by a culturally reinforced reticience to utilize these services. Haji (Japanese for shame) would tend to affect the individual and the family because of the stigma attached to the family's inability to resolve the situation. Additionally, culturally based requirements for politeness, would place immediate hesitations on an individual or family to impose upon their cultural institutions, knowing that the resources of the institution would be sparse. Under these internal conditions, handicapped persons within Asian ethnic communities, usually lived in neglect and isolation.

SERVICE DELIVERY BARRIERS

The history and cultural values of Asian Americans in the context of their settlement in the United States provides major barriers to service for the handicapped in these communities. The individual and family, the ethnic community, and the dominant society all maintain mutually reinforcing barriers to service.

Cultural hesitation, family shame and disability act as barriers on the individual to find means of remediation or rehabilitation of their condition. The development of alternative institutions, community attitudes, community image and community self image interfere with the development of alternative institutions, community attitudes, community image and community self image interfere with the development of service delivery systems appropriate to Asian American handicapped persons. The invisibility of the needs of ethnic handicapped, the inability to respond to cultural and linguistic needs of the ethnic handicapped, and fear and mistrust by ethnic consumers, act as barriers for Governmental and other major service delivery agents to interface with Asian ethnic communities.

The net result of these factors is that no organized effort to address the unique needs of Asian American handicapped persons was developed until very recent times. Two projects related to the handicapped individuals in the Asian American community began in the Los Angeles area one year apart. In 1971, the Oriental Service Center Allowed its Program Development Specialist to initiate efforts toward the development of a sheltered workshop facility that could serve a predominant Asian American clientele. A year later, the Japanese Community Pioneer Center supported a Japanese American Sightless Institute Project that was funded initially through Social Rehabilitation Service, Department of Health, Education and Welfare. The first efforts to reach Asian American handicapped develops more than 150 years after they began arriving on American shores. The experience of these two entities remains the only basis from which any current insight on handicapped Asian Americans can be found. Conveniently, the sheltered workshop incorporated as a separate entity under the name, Asian Rehabilitation Services, and the Japanese American Sightless Institute joined the former agency in early 1975. The following sequence of service delivery concerns represents perspective derived from the two interrelated projects.

POPULATION IDENTIFICATION

Because of the historical lack of service delivery to handicapped Asian Americans there has developed an assumption within the target group that there is little alternative to the neglected and isolated existence that they experience. The social deprivation of this experience adds to the negative self image of the population and, in effect, prevents the affirmation of efforts to be open to change. Additionally, many handicapped persons experience a long term existence under the protective atmosphere of a highly structured role in the family. New experiences for this population are highly threatening, as appropriate role responses are not structured for the handicapped, as they would be in the existing family setting.

In responding to this situation, an obvious need for community education and community validation of the effort is required, before handicapped persons within the ethnic community can be identified. As the Asian American communities tend to be institutional rather than geographic, the existing community institutions are major targets for re-education and validation. The re-education process for the ethnic community is critical in that community institutions, in a large part, affect family attitudes toward allowing and seeking services for family members.

Potential service delivery consumers are more likely to seek services with family originated support and validation. Equally significant is the users understanding of eligibility requirements, as ambiguity on eligibility may be understood by the potential service user as a potential conflict situation. Conflict situations are likely to be avoided by Asian American handicapped persons.

The experience both of Asian Rehabilitation Services and Japanese American Sightless Institute, has been the identification of high anxiety of new clients. This anxiety is somewhat reduced if the initial contact remains within a community setting that contains elements that are familiar to the person. Bilingual literature, bilingual staffing, respect for culturally familiar protocols and like features greatly enhance the ability of both referral and direct service agencies to attract Asian American service users.

A complicating caveat in implementing a target group outreach effort is the variance in organization of particular ethnic communities. Generational variables, degree of newness to the country of community, population numbers, geography and culture are considerations that must be assessed for different ethnic communities and for different community settings around the country.

TARGET CHARACTERISTICS

Handicapped Asian Americans reflect their population as a whole. Demographic detail will be comparable to the general ethnic population with which the person identifies. However, the historical neglect and reticence to receive service may reflect a greater severity of impairment in the client population. Historically, Asian Americans have developed a mistrust for public service delivery agents. Cultural values tend to restrict the utilization of internal community resources. Together, these two factors tend to discourage service delivery utilization unless no options are available. Under these conditions, a significant portion of the service applicant population is likely to have fairly great service needs at enrollment. This dynamic in the Asian American population is common in other human service delivery systems. Paralleling this characteristic, may be accompanying feelings of shame and guilt for having the need for service, and much anxiety regarding confronting an unfamiliar situation. Anxiety levels may vary depending upon the degree of familiarity and trust that the service provider can demonstrate to the new client. In general, Asian Americans tend to develop trust more easily within a setting that is culturally and ethnically familiar. Conversely, they are apt to feel greater shame in that same setting, assuming a shared value with the service provider of the same ethnicity.

To illustrate the degree of anxiety and apprehension that Asian Americans have toward public service delivery agents, the entire Japanese American Sightless Institute participant population made known their intention to resign from activity in the project when the California Department of Rehabilitation insisted that the participants would necessarily have to become concurrent clients of the Department. Participants resumed project activity only after assurances that they would not be forced to enter the State's caseload. The participants in this project had individual experience or heard stories of negative experiences within the state system. The mutual sharing of these "horror stories" was enough to prevent any of these participants from considering utilizing state services. Only after several arranged interactions with state staff, did the anxiety of the participants relax sufficiently enough to have a few persons attempt to investigate state services.

SUMMARY

Asian Americans are in the peculiar position of having experienced a history that has resulted in the development of individual and community values and attitudes that are often incongruent with the service delivery vehicles that exist in the public sector. Until very recently, the invisibility of the needs of handicapped Asian Americans concealed the incongruency of the delivery system. The development of two projects in Los Angeles to provide an interface, bridging the gaps between the handicapped person and the ethnic community, and the ethnic community and public service deliverers, will probably encourage the development of similar efforts elsewhere. Such efforts will be necessary if Asian Americans are to be provided equal opportunities to develop full potenital.

BIBLIOGRAPHY

Chomori, Karen; Hatanaka, Carol; Higashioka, Cathy; Ishino, Herman; Sakamoto, Kengo; Uyekawa, Gary; Wakabayashi, Ron, and Chan, Sam *Japanese American Sightless Institute Project* (Final Report). U.S. Department of Health, Education and Welfare, Social Rehabilitation Service, Division of Research and Demonstration Grants. Grants No. RD-08-55949. June 1974.

SECTIÓN II
UNIQUE PROBLEMS OF HANDICAPPED BLACK AMERICANS

INTRODUCTION

One of the most pressing areas of challenge confronting contemporary society is that of helping Blacks who may be physically, mentally, emotionally, or socially handicapped translate their potential into self-fulfilling social and economic roles. This challenge is magnified by

the pervasive discrimination and segregation in employment, education, and housing that continues to exist. As a result, a great number of handicapped Black Americans are excluded from the benefits of economic progress.

Handicapped Black Americans have suffered from the same indignities and racist attitudes as the non-handicapped Black American population. As noted by Washington (1968), the United States is institutionally racist. Some forms of racism are blatant, for example, the cultural and legal restrictions of the South. Other forms of racism are more subtle, such as standards of beauty, acceptable speech, the promises of advertising, and the quality of education all of which are white.

Racism is expressed by many attitudes such as hatred or intolerance for those who are racially different. As noted in the report of the President's National Advisory Commission on Civil Disorders (1968) the 1967 riots were brought about by white racism, coupled with the lack of progress in providing Blacks equality in education, jobs, and housing. Yet whites, particularly those in our political, economic, educational, and social services, have not come to the point of accepting sacrifices to alleviate the plight of Blacks. On the other hand, there are clear and ominous signs that the patience of Black men with White unwillingness to take action is running out. The violence in our cities in the 1960s and early 1970s, in part, represented anger of the Black American who had been frustrated by the continuing chasm separating the protestations of equality from the persistent reality of second-class citizenship.

Lincoln (1968), Carmichael and Hamilton (1967), Silberman (1964), Kozol (1967), Brink and Harris (1966), and others have also pointed out that America is a white racist society. This indictment is of the total white society and not a segment of the society. As a result, Black Americans, in recent years, have actively challenged the traditional white, middle-class–oriented public and private institutional systems in an attempt to achieve equality of opportunity, social emancipation, and justice. In doing so, many Black Americans have adopted the belief of Malcolm X (1963) that racism is so deeply ingrained in white America that appeals to conscience would bring no fundamental change. Hence, the concept of Black Power emerged, reflecting the Black American's drive for independence, racial pride, and self-respect. This new mood, which places emphasis on self-help in the political, economic, and educational spheres as well as racial unity has provided impetus to the Black American's pursuit of equality.

The Black American's independent quest for equality and to solve his own problems has precipitated and increased the manifestation of racist attitudes among many whites. Some have even labeled all Blacks as racists. It may appear, therefore, that we are moving toward two societies as a result of such racist attitudes—one black, one white—separate and unequal.

In responding to the challenge of helping handicapped Black Americans develop to their fullest potential, society needs to undertake four basic activities. These activities are as follows:

1. Obtain accurate statistics on the incidence of handicapping conditions among Black Americans. A comprehensive system must be designed for identifying Black Americans who are handicapped and in designing this system, two factors must be taken into consideration. First is the definition of the handicapped and its applicability to Black Americans. Second is recognition of past abuse and exploitation of Black Americans as subjects for research which have yielded little, if any, direct benefits for them.

2. Examine the present social and rehabilitation service delivery systems. A survey of public and private social and rehabilitation service agencies in the U.S. would reveal that the number of handicapped Black Americans served by these agencies is negligible. In view of this, one cannot help from raising the question as to why Black Americans are not being served by these agencies. Are these agencies equipped to serve the racially different clients and respond to their unique needs? Is the service delivery system presently being used for serving the handicapped population at large viable for the handicapped Black American?

3. Develop a pool of manpower resources for social and rehabilitation services that can relate to the handicapped Black American. It would be absurd to assume that all professionals in social and rehabilitation services can deal effectively with handicapped individuals from ethnic minority groups, but those who can need to be supported and provided educational opportunities for increasing their competence in this area. Moreover, it may be necessary to develop

new manpower resources to serve the handicapped Black American. Several social and rehabilitation service programs have experimented with the idea of using support personnel—individuals from the community and of the same racial background of the clients being served—and found them useful. Regardless of the composition of the manpower resources for serving the handicapped Black American, they must be equipped with the knowledge and skills to deal with people who may have handicaps over and above the primary one. In the case of the Black American, professionals must not only be able to deal with handicapped Black Americans in relation to their physical, mental, emotional, or social handicapped, but also help these individuals deal with the additional handicapping conditions caused by discrimination and prejudice because of their racial background.

4. Develop human relation programs and make them mandatory for all professionals in social and rehabilitation services to sensitize them to the Black American and other ethnic minority groups. Many professinals do not understand how and why handicapped Black Americans think, feel, and behave the way they do. They do not understand the unique problems faced by Blacks in dealing with the day-by-day prejudices perpetrated upon them. Of most importance, professionals in social and rehabilitation services lack experience in dealing with handicapped Black Americans who have different motivational patterns and values. As Rogers (1961) so eloquently stated about the goals of counseling, "To be facilitative toward another human being requires that we be deeply sensitive to his moment-to-monent experience, grouping both the core meaning, significance, and the content of his experience and feelings."

Of course, there are many other activities one must consider if society is to help the handicapped Black American develop to his/her fullest potential. The four basic activities mentioned above represent the most crucial ones in need of attention at this time. An obvious and common denominator for all four activities is "understanding." Society needs to better understand the unique problems faced by the handicapped Black American. In response to this need, the remainder of this paper is devoted to a discussion of the major problems faced by the handicapped Black American in trying to translate his/her potential into self-fulfilling social and economic roles.

SOCIETAL ATTITUDES

The problem which constitutes the most crucial barrier to the successful adjustment of handicapped Black Americans is societal attitudes. Societal attitudes more than any other variable dictates the type of treatment provided them and also influences the development and implementation of programs to meet the diverse needs of handicapped Black Americans. A historical synopsis of society's treatment of the handicapped, in general, reflects that attitudes have fluctuated widely from negative ones of extermination, ridicule, and asylum to positive one of education and rehabilitation, i.e., providing the handicapped an opportunity to develop to his fullest physical, mental, social, educational, vocational, and economic usefulness. This transformation of negative to positive attitudes on the part of our society, however, has not been completed and is still in transition. Many unfounded negative attitudes still exist in areas which provide the basis for prejudice toward the handicapped person. Gellman (1959) attirubtes such prejudice toward the handicapped by the nonhandicapped in modern society to three deep and often unconscious mechanisms: (a) a belief that physical abnormality is a retribution for evil, and hence the disabled person is evil and dangerous; (b) a belief that a disabled person has been unjustly punished and is therefore under compulsion to an evil act to balance the injustice, and hence that he is dangerous; and (c) the projection of one's own unacceptable impulses upon the disabled, and hence that they are evil and dangerous. These same factors which are applicable to both the nonhandicapped and the handicapped Black American, are not "often unconscious" but "conscious" mechanisms.

Blacks have not been admitted to full membership in our society, and Americans are now faced with the question of whether they really believe in their expressed values of equality and freedom. As noted by Wright (1959), in her basic principles and assumptions underlying rehabilitation, every human being is of worth, to be respected and cherished, no mattter how severe his handicaps may be. Handicapped Black Americans have a right to be respected and cherished, no matter how severe his handicaps may be. They have a right to be assisted in the unfolding of their personality and the development of their potentialities, for their own sake and the good of society.

McGowan and Porter (1967) support this when they discuss the two basic assumptions underlying the formation of special programs for the handicapped: (a) Every member of a democratic society has an inherent right to the opportunity to earn a living and make his contributions to society, and (b) society has the obligation to equalize, as best it can by special services, the handicapped person's opportunity to earn a living equal to the opportunity possessed by nonhandicapped members of society.

ATTITUDES OF PROFESSIONALS

Another problem which affects the successful adjustment of handicapped Black Americans is the attitudes of professionals who provide social and rehabilitation services. As mentioned earlier in this paper there is a need for greater awareness and understanding among these professionals of Black Americans. They need to understand how white racism is manifested in discrimination in education, housing, employment, and other vital areas—the antithesis to the concept of equal opportunity for the Black in a democratic society. Since many professionals in social and rehabilitation service agencies live in protective and isolated environments and may support the continuation of such racist attitudes, it is incontestable that such attitudes transfer themselves into their professional endeavors.

The vigorous drive for equality by Black people during the past few years has generated multitudinous repressed feelings of fear and hatred among the whites in our society. Unfortunately, these prejudicial attitudes adversely influence the attitudes and action taken by professionals in assisting the handicapped Black to develop to his/her fullest potential. A complicating feature implicit in such negative attitudes among whites is the mythical belief that all Blacks are lazy, shiftless, fearless, lewd, ignorant, immoral, and vicious.

When professionals are questioned regarding the provision of social and rehabilitation services to the handicapped Black Americans, the typical defensive responses are: "Blacks won't apply for our services"; "they are not motivated"; "they apply for services but fail to follow-through," and a host of other mythical notions. Frankly, what professionals are reflecting is that they do not care to work with individuals who may constitute a challenge and make the probability of success unpredictable. Why should the handicapped Black American follow-through on his application for services when the professional who is suppose to provide assistance displays an indifferent (often negative) attitude toward him/her and his/her requests?

How often do professionals forget that messages can be transmitted through general attitudes, voice tone, posture, and other paralingual means by which we communicate reinforcement or denial? Whey should the handicapped Black American trust a white, middle-class, professional who may communicate sincerity and understanding in the helping relationship, but after working hours supports and actively participates in programs directed toward the oppression of Black people? They are aware of all these morally offensive realities. Yet, some professionals in social and rehabilitation service agencies turn their backs or bury themselves in their professional endeavors and escape through the defensive reaction of denial, repression, or intellectualization. Some do virtually nothing to help alleviate the serious problems that exist.

Attitudes are formulated out of knowledge and experiences and are significantly influenced by the environment in which the person lives. This explains why many whites have retained prejudiced attitudes toward the Black. They do not understand Blacks, their culture, style of life, values, and attitudes, and virtually have no accurate knowledge and experience in dealing with them. The lack of experience, in particular, inevitably creates and perpetuates fear, anxiety, hostility, apathy, and indifferent attitudes. Moreover, it is extremely difficult for whites to accept the fact that there are individual differences within the Black society. Rather, they tend to classify all Blacks into one large group that fits their stereotypes and massages their ego and feelings of superiority. The Black is viewed not as a human being, who may have suffered the plight of discrimination, but as a morally evil person who has created complex problems for himself and society. With this value orientation present in society, it may be difficult for professionals to feel compassion for or empathy with the handicapped Black American.

If professionals in social and rehabilitation agencies are going to increase their efforts in serving the handicapped Black, they are going to have to examine and change some of their attitudes. It is impossible to objectively help the

handicapped Black develop to this fullest potential if prejudiced attitudes are not recognized and dealt with by the rehabilitation worker himself.

Many attitudes can be modified as a result of increased awareness, knowledge, and exposure. Professionals must actively seek information and experiences for a better understanding of the handicapped Black American. Experience is an excellent modality for teaching people of the problems of the handicapped Black. Many can learn from experience and can develop the necessary attitudes and sensitivities essential to helping these potential clients proceed through rehabilitation.

In pursuit of information and experiences for a better understanding of Blacks, particularly those who may be physically, mentally, emotionally, or socially handicapped, professionals in social and rehabilitation service agencies also need to do the following:

1. Develop a sincere desire and commitment to help Black clients.
2. Develop in their agency a library of books, papers, and periodicals dealing with Black history and culture.
3. Learn and respect the language patterns of the Black client so that they can communicate adequately with him.
4. Help overcome the dehumanizing procedures of the present rehabilitation system.
5. Have dialogues with a wide variety of Black citizens.
6. Develop and participate in sensitivity training programs designed to deal with rehabilitation workers' attitudes toward Black people.
7. Develop and participate in in-service training programs designed to help them gain knowledge and understanding of the Black. Include visits to Black ghetto areas and make an effort to secure, show, and evaluate films and videotapes with Blacks and their problems.
8. Start listening to what Black clients have to say about their needs, social and rehabilitation services.
9. Become involved in community action projects and other community activities in the ghetto.

COMMUNICATION

Communication is another problem which affects the successful adjustment of the handicapped Black American. Communication represents the basic foundation for interaction between individuals and the development of viable human relationships. It influences our attitudes and actions toward people. In particular, communication can influence attitude change in a positive direction if the source is highly credible, while sources having low credibility either do not affect attitude change or swing it in a negative direction.

Walker (1968) in his article "The Disadvantaged Enter Rehabilitation—Are Both Ready?" found that one of the primary problems with traditional techniques in serving the disadvantaged, particularly minority clients, was communication. He indicated that at their rehabilitation center they made the mistake of talking to the disadvantaged as if they were middle-class neurotics. Walker stated that:

> Our interviews involved such classics as "improving one's relationship with others" and "feeling of alienation." This process seemed to be rewarding to the staff, but our clients were never quite sure what we were talking about. They continued to insist that they only wanted a job. Worse yet, their relationships did not improve.

Walker further pointed out that their first step in correcting the communication problem was to reduce to a bare minimum vague terms such as "motivation" and "personal adjustment." He insisted on the staff using operational terms which could be clearly understood by both parties. Slowly the staff began to use statements such as "other people don't like you," instead of "your relationship with others appears to be a problem."

The inability to penetrate the language barriers of the handicapped Black American renders middle-class professionals in social and rehabilitation service agencies helpless. They usually communicate in abstractions and words that not only convey motivations, but that transmit, modify and refine feelings as well. In fact, professionals hardly consider their services successful unless their clients verbalize their feelings fluently. Unfortunately, such fluency is rare with handicapped Black Americans, most of whom communicate with great economy of language. Their speech is characterized by a reduction in modifiers, adjectives, and adverbs, especially those which qualify feelings.

If a helping relationship is to be productive, there must be maximum communication between the parties involved. Words, whether spoken or written, are symbolic for various aspects of man's experience. They represent objects, actions, relationships, and constitute, in effect, a code. In order for verbal communication to occur between parties, there must be shared understandings, common ideas, concerning these words. When the counselor speaks, the words he says must have meaning for the listener. Likewise, when the handicapped person speaks, the professional must know what the words, as used by the speaker, stand for. Both persons in short, need to know the code. Because the middle-class professional and the handicapped Black American have such divergent experiential backgrounds, communication may be impeded by the lack of a pool of shared understanding.

Professionals in social and rehabilitation service agencies must learn the language patterns of clients so that true meanings are being communicated. However, at all cost, avoid mimicking the handicapped Black American's colloquialisms. They must recognize the difficulty he/she has relating to them. Thus, any attack or perceived attack on the handicapped Black American will jeopardize the helping relationship.

In helping the handicapped Black American, hardly any attention is directed toward non-verbal communication. They can quickly pick up non-verbal cues that betray a professional person's real feelings. A grimace, tone of voice or appearance may convey far more than words. Professionals, therefore, need to become adept at understanding the non-verbal signals and signs used by the handicapped Black American in expressing himself. In addition, professionals need to demonstrate non-verbally or through action to the handicapped Black American the desire and commitment to help them. The most vital characteristic that must be conveyed is true sincerity.

ATTITUDES OF HANDICAPPED BLACK AMERICANS

Another problem that affects the successful adjustment of handicapped Black Americans is their attitudes toward themselves. Handicapped Black Americans basically lack familiarity with the services offered by social and rehabilitation agencies and manifest a high degree of skepticism regarding them. Middle-class people have had from infancy a continuing series of relationships with professionals and friends who assist them in some way. These contacts, in the main, are verbalizing relationships. The roles of the assister and the assisted are clearly understood. With handicapped Black Americans, such roles are not as clear cut and therefore, dissemination of information is more important to them.

It cannot be overemphasized the necessity of dealing with how the handicapped Black American feels about himself/herself and those obstacleses that he or she must come in contact with in life. It is not so important how the professional thinks he should feel, but how he/she does feel. Handicapped Black Americans should have the freedom to express their true feelings. It should become the professional's objective to help them to work through their doubts by carefully understanding the forces acting on them and trying to see things through their eyes. Professionals should not look for that automatic, middle-class respect that they have been accustomed to. Respect is a two-way street and must be earned by deeds and actions.

Many handicapped Black Americans hesitate to reveal themselves psychologically which also influences the helping relationship. Research suggest that in American society, self-disclosure is directly related to how the individual has been treated in society. Individuals who have been treated harshly and have experienced hardships are reluctant to share their hurts with anyone, even their most intimate friends. Handicapped Black Americans are very careful in revealing their real feelings regarding professionals and the social and rehabilitation service system. They may disguise their feelings of frustration, alienation, and hostility in a variety of ways.

Professionals need to recognize the differences in values and conflicts within the handicapped Black American's culture without becoming judgmental. They should not try to re-shape them, but accept and clarify their values and help them improve within the scheme of these values. At the same time, we need to be sympathetic toward, respect and even enhance the handicapped Black American's values to reach him/her. Although Black Americans need to exercise their own values and develop their own thinking in context with their life style and culture, professionals need to provide them

with the new information about themselves, their environment and their possible future.

SUMMARY

This paper has dealt with some of the major concerns and factors influencing the successful adjustment of handicapped Black Americans. It did not include a detailed analysis of all the problems experienced by these individuals in relation to their education, environment, community, and employment possibilities. Rather, the paper focused on selected problems—society attitudes, attitudes of professionals, communication, and handicapped Black American attitudes which represent the key factors in understanding handicapped Black Americans and their unique problems.

The successful adjustment of the handicapped Black American can help alleviate the nation's domestic and racial problems. Current developments in society suggest that the decision-making time is here if we seriously want to solve our human problems. Yet, the most potent force affecting such an endeavor is attitudes. The future requires new kinds of attitudes, particularly among rehabilitation workers, if they intend to meet their commitments in rehabilitating handicapped persons, regardless of race, creed, or national origin.

REFERENCES

Barker, R. & Wright, B.A. The social psychology of adjustment to physical disability. In: James F. Garrett, (Ed.) *Psychological Aspects of Physical Disability*, Washington: Vocational Rehabilitation Administration, 1953.

Brink, W. & Harris L. *Black and white*. New York: Simon and Schuster, 1966.

Carmichael, S. & Hamilton, C. V. *Black power*. New York; Vintage 1967.

Gellman, W. Roots of prejudice against the handicapped. *Journal of Rehabilitation*, 1959, 25, 4-6, 25.

Kozol, J. *Death at any early age*. Boston: Houghton Mifflin, 1967.

Lincoln, C. E. *Is anybody listening to black America?* New York: Seabury, 1968.

Malcolm X & Haley, A. *The autobiography of Malcolm X*. New York: Dell, 1963.

McGowan, J. G. & Porter, T. L. *An introduction to the vocational rehabilitation process*. Washington: Rehabilitation Services Administration, 1967.

National Advisory Commission on Civil Disorders. *Report of the national advisory commission civil disorders*.

Rogers, Carl R. *On Becoming a Person*. Boston: Houghton Mifflin, 1961.

Silberman, C. E. *Crisis in black and white*. New York: Vintage, 1964.

Washington, K. S. What counselors must know about black power. *Personnel and Guidance Journal*, 1968, 47, 204-208

SECTION II
UNIQUE PROBLEMS OF HANDICAPPED NATIVE AMERICANS

INTRODUCTION

Any position paper which purports to address itself to conditions affecting the "Native American" population must begin with a definition of what constitutes a "Native American," how the definition is arrived at, and the limitations of such a definition.

For purposes of this paper, Native Americans are considered to be those persons of Indian, Eskimo, or Aleut descent who are eligible for services provided by the Indian Health Service; this definition limits the population to some 500,000 persons residing in 26 States on Federally recognized reservations or in Alaskan villages. Another 500,000 persons live in urban areas at the present time and, for purposes of the paper, have generally lost their Indian "identity" by virtue of their place of residence. An undertermined number of other persons of Indian descent, who reside on State reservations and are, therefore, not Federal beneficiaries, are also not included in this report.

DISCUSSION OF THE PROBLEM

Two major problems drastically limit the scope of the paper. The first is that comprehensive data on all handicapping conditions simply do not exist since the Indian Health

Service does not now keep statistics on the number of persons with conditions consdered handicapping. Many Indian children who are handicapped are cared for by State Crippled Children Services but States may vary greatly in determining what conditions they consider to be handicapping. Mental retardation and severe behavioral disorders are not included in State Crippled Children's programs; learning disabilities are usually excluded from State programs and even deafness is not considered handicapping in some States when it comes to determining whether or not the State can provide a hearing aid for a deaf child. Degree of impairment and disability need to be considered in determining an individual's inclusion on a list of the handicapped, but none of the information which follows gives such a breakdown. These estimates are laregly based upon previously presented testimony to Congress, State Crippled Children registries, Head Start enrollment data, numbers of institutionalized children, and hospital admissions.

A second limiting factor in determining the extent of handicapping conditions is the tendency among many Indian communities to absorb the handicapped, or other "different," person within the structure of the society. Many Indian communities are characterized by very extended family relationships so that the handicapped person can be cared for within the family or within the community at large. Estimates of the number of deaf Navajos, for instance, have been extremely hard to come by since many Navajo persons are known to be deaf who spend their lifetimes herding sheep a vocation which they are capable of pursuing and which has a great deal of value within the Navajo community. While there are Navajo children enrolled in various State schools for the deaf, the means for determining what proportion of those actually needing special education cannot be arrived at. As might be inferred from the foregoing, the accpetance of "deviance" is higher among many Indian groups than the contemporary American society as a whole. In some groups, for example, the child born with a handicap is not evaluated negatively since it is assumed the child has the prenatal choice of how he wishes to be born and, if handicapped, is so by choice. Some Indian languages also show a great deal of sophistication in recognition of the problem. The Ute term *n'kvat* ("can't hear so can't talk") is much more highly descriptive of the condition than are the corresponding English terms "deaf and dumb." In common with other tribal characteristics reflected in language the Ute term implies no value judgment of the condition. While there seems to be little question that the person with a severe handicap is recognized as being different in the Indian communities, by and large such difference is accepted within a wide range of tolerance. By contrast, prosthetic devices do not seem to have the same acceptance in some Indian communities. While perhaps a reflection of childhood generally, anecdotal accounts of Indian children ridiculed for wearing either eyeglasses or a hearing aid are rather abundant. Ridicule does not seem to be associated with the condition requiring the prosthetic device, however.

In writing of given groups of persons, recognition of an attitudes toward handicapping conditions the risk towards over generalization nees to be avoided. There seems to be a tendency in much of the literature to generalize the "Indians" as if they were a very homogeneous group of people, particularly with respect to attitudes, mores, religious beliefs, and attitudes. In fact, variations of attitudes and beliefs are as common among Indian communities as any other segments of society. Sapir (1951), as mentioned below, was an early observer of a particular segment of Indian societies' attitudes towards disfiguring or handicapping conditions. More recently, Bergman (1968) has noted in Navajo boarding schools the activities of Navajo children which would not seem to fit the generalized position stated above:

Group hostility is often directed at scapegoats. In a situation where large groups of children are constantly together with rigid but not very close adult supervision, opportunities for teasing are particularly great. I regularly see depressed, masochistic children who have a special proclivity for being baited, and the baiting is often extreme. Children with physical deformities are also often badly treated by their classmates, and there is little the out numbered dormitory staff can do about it.

Children with seizures are in an even worse position. Seizures are cause for alarm and disgust among traditional Navajos. They are thought to be caused by incest or haunting by the dead, and are sometimes taken as a sign that the affected person is a witch. Children with seizures are usually stigmatized and ostracized, but they can and often do strike back. Many of them learn

that the attacks frighten the other children so much that they can be used as a weapon. They then develop a large stock of pseudoseizures with which they can sometimes dominate the life of their dormitory. I once attended a conference about one girl, who besides her grand mal seizures, which were well documented clinically, had other attacks which the school called "her running seizures." When aggravated, she would begin to yell and run madly about the room. When she did, the other sixty girls in the dormitory would all run out the doors. I asked the dormitory attendants what they did, and one answered, "We hide in the closet."

In summary, the following are particularly significant problems in determining the extent of handicapping conditions affecting American Indians and Alaskan Natives:

1. lack of information sources reporting on handicapping conditions;
2. lack of definition of the extent of what constitutes "a handicap" in the cross-cultural sense. From the foregoing, it seems apparent that "handicap" is a highly variable term meaning different things to persons within different cultures. This is particularly a problem in providing services to Indian beneficiaries if, as in the instance cited above, a child "wanted to be born" with a cleft palate. People in this group would appear to be less likely to consider such a child "handicapped" although the prevailing non-Indian community surrounding this reservation would certainly view the child this way when he entered public school. As also mentioned above, the Navajo child wearing a hearing aid may be more likely the considered "deviant" by virtue of the prosthesis than on the basis of the handicapping condition.

BEHAVIORAL-EMOTIONAL DISORDERS

Bryde (1967) reported that for the Oglala Sioux in South Dakota a 60% school drop-out rate between grades 8 and 12 was an indication of poor mental health. In his research he compared Oglala Sioux students with non-Indian students and found significantly greater personality disruptions on the part of the Indian students on such variables as rejection, depression, anxiety, withdrawal tendencies along with social, self, and emotional alienation. Bergman (1968) points out one of the major reasons for such disruption as it affects Navajo children when he notes that the Navajo child coming into an English speaking environment is analagous to anyone of us suddenly being enrolled in an astronomy class at Moscow University and being expected to learn classes taught in Russian. Bergman elaborates on the problem as it affects education achievement:

> In the world of the boarding school not only the Navajo language but almost all things Navajo are rated very low. The children are frequently told not to be like their parents and are often admonished against following the traditions of their people. One middle-aged woman told me that she went to school in the days when few Indian children were enrolled and she went more or less against the wishes of her parents. She had been eager to go to school and did well in her first two years, but then left suddenly. I don't believe that the school knew the reason for her leaving but she told it to me. Her teacher one day was angry at the laziness of the class and said, "If you want to live in a hogan for the rest of your life just don't bother to study." Since this women definitely did want to live in a hogan for the rest of her life, she left school. There are other bizarre consequences of this system. In my consultations with school personnel I often encounter instructional aides who pretend not to speak Navajo. They have become so convinced that speaking Navajo is a bad thing to do, that they often won't admit that they can. The children learn that what they say in Navajo is effectively kept secret from the authorities even if one of the Navajo-speaking members of the staff hears them, because the Navajo staff member will be too ashamed of having understood to tell anyone.

The effects of such an environment on the child obviously interfere with more than his educational achievement. Bergman further describes the resultant hostility which evolves and

at the same time provides some insights into how certain handicapping conditions are viewed from the traditional Navajo point of view.

From Alaska, Nachmann (1969), describes what she calls "the main types of non-physical interferences in learning the intellectual development which hamper the Native student":

1. Lack of early stimulus to learning: "The pre-school years for the largest and most crucial intellectual development takes place are years of extreme stimulus deprivation for many Native children. The climate precludes outdoor play for a large portion of the year. The out of doors in the Artic provides a highly simplified sensory environment. The average home is a meagerly furnished one or two room structure, largely devoid of toys, books, pictures, musical instruments, indeed most of the sensory input which stimulates the urban childs' development." (P.498)

2. Interference in character development: "Prolonged or repeated separation from parents (due to hospitalizations of parents or children, removal of children to boarding schools, and other kinds of family disruptions) remain a common occurrence for Alaskan families." (P.499)

3. Interference in development of capacity to sublimate: "The use of the intellect, if it is to preceed at all beyond simple note learning, depends upon their having occurred in childhood the development of this capacity to transform the basic instinctual energies into intellectual ones . . . it is difficult to provide the necessary conditions for this development in a crowded one room house where the sexual activity and the destructive violence that life entails must be viewed at close range by every member of the household." (P.533)

4. Separation of education from other meaningful experiences: "There exist for many children not only the temporal discontinuities in personal relationships mentioned above, but also a sharp discontinuity between schooling and other meaningful experiences." (P.533)

5. Teacher-student attitudes which inhibit learning: "Because of its linguistic and cultural strangeness participation in the classroom routine is experienced by many children here as exposure to criticism and to the danger of being found wanting—the aim becomes to conceal ignorance and to avoid embarrasement by saying as little as possible and keeping uninvolved. School becomes a continuously defensive ordeal to be survived." (P.499)

6. Perpetuation of gaps in basic skills: "Through the wide spread practice of 'social promotion' . . . children who have failed to acquire the basic language and arithmetic skills upon which all subsequent learning is dependent or pushed along through the grades according to age rather than achievement. As a consequence what is taught become increasingly unmeaningful, and the entire educational process increasing an empty compliance with a ritual requirement." (P.499)

7. Lack of supervisory aid for teachers: "The lack of intensive local supervision and the disadvantages of 'absentee administration' to a problem which stems from Alaskas' immense distances and which education hence shares with many other occupations. Teachers are frequently new to Alaska, new to the ways of life in the remote north, and new to teaching at once. They are cut off from the means to professional stimulation and development which are available elsewhere." (P.500)

Nachmann recommends that handicapping emotional and mental conditions resulting from these problems could be changed within the educational system through recognition of the undereducation of the Native as a universal problem, through elimination of social promotion, through recognition of preschool and adult education are essential to the success of the regular school program, the bilingual Indian and Eskimo teachers and aids be trained and used, and that higher trained supervision and in-service training be provided on the local level.

Also specifically to Alaska, Fleshman (1969. P. 529-531) notes that the Alaskan Native child suffers an excessive amount of illness to the extent that roughly 15% of such children are hospitalized each year. He observes that there are two major effects on the children, the first is direct and related to disease and the second is indirect and related to nonspecific factors such as separation from parents and prolonged hospitalization. In the latter case, particularly, significant emotional problems can result when we see that many Native children have become ill in the village, must be taken to the field hospital and then are often transferred up to 600 miles to a referral hospital where they may spend several months and then return home. He states that a number of such children who as

infants were separated from their parents were, at about 10 to 12 years of age, having difficulty in relating to their families, were failing in school, and were also failing to grow in normal physical fashion even though separation may have resulted from a parent who was ill rather than the child.

Other socio-cultural factors relating to handicapping conditions in Alaska include mental retardation, which is difficult to determine since no one has yet devised a reliable test that excludes sociologic factors. Such factors combined with infectious diseases such as meningitis lead Fleshman to conclude that probably every Alaskan village will contain at least two school age children who are mentally retarded. He concludes (P. 530-531): "The diseases that we are dealing with are essentially unmanageable by traditional medical means. They disappeared as killers and cripplers many years ago in the rest of the United States, yielding to correction of the environmental factors responsible such as housing, sanitation, nutrition, and education. I feel that it is imperative that the education system consider the tremendous gap that exists between the Alaskan Native pupils and the average child in the United States and to realize that poorly nourished, physically handicapped or chronically ill children cannot learn nor achieve in a competitive society. The curriculum must contain a much stronger emphasis than it now does on learning about sanitation, nutrition, basic, and, especially, reproductive physiology until the time these children are able to accept and utilize the contents of the traditional United Stated curriculum."

COMMUNICATION DISORDERS: OTITIS MEDIA

For reasons other than the author's professional bias, the one plea from which data on handicapping conditions exists to some extent is the field of communication disorders, particularly for hearing loss associated with otitis media. Since 1961, when it was first listed as a reportable disease, otitis media has ranked no lower than second in frequency of report annually. In 1962 the reported disease rate was 3,801/100,000 and 1974 was 10,958/100,000. The increased prevalence is probably a result of both better case finding procedures and increased disease rates. In 1969, Fleshman (P.530) reported that hearing loss primarily resulting from chronic ear disease was the number one disability capable of interfering with education and learning in Alaska and that many surveys indicated that 10% of the population had chronic ear infection with 1/4 of these having the involvement to the extent that hearing acuity was impaired. At that time in Alaska at least 625 school children had a serious handicap with many more, up to 1/3 of the population, suffering acute infections during infancy and early childhood. Also in 1969, Deuschle (pg. 537-553), reviewed the available literature regarding ear disease and hearing loss affecting Indians and Alaska Natives. He reported that hearing survey conducted by the State Audiologist found that in Bethel 53% of the males and 39% of the females in the first through eleventh grade had a hearing loss of 26 decibels or more and noted that handicaps of this magnitude would have far reaching consequence throughout the entire lifetime of the affected person. He also noticed the difference in prevalence in citing a table presented by Johnson (R.L. Johnson, "Chronic otitis media in school age Navajo Indians," Laryngoscope, Vol. LXXXVII, No. 11, Pages 1990-95, 1967) which showed that hearing loss in one or two ears in the general population equal 1.2% while for Indian children in British Columbia it was 31%, for Aleut children it was 26%, for Alaskan Indian children it was 23% and for Eskimos' it was 34%. In the same study, Johnson reported a prevalance of chronic otitis media at 7% with one out of four having a bilateral involvement. (More recent information gathered from Navajo, unpublished, indicates clinic otitis media rate averaging 10% with some boarding schools as high as 13%). A smiliarly high prevalence was found by Zonis ("Chronic otitis media in southwestern American Indians. I. Prevalance. *Archives of Otology* Volume 88, Pages 40-45, 1968). More recent reports to Indian Health Service indicate an overall prevalence of chronic otitis media equalling 5% throughout the Indian Health Service population; this figure would indicate a reservoir of 22,000 unoperated patients in a non-Alaska population (Stewart, 1975).

ADDENDUM

Probably the most pressing general need insofar as handicapping conditions among Indian persons is concerned is the same problem that faces delivery of health services generally. The

average Indian income is still in the neighborhood of $2,000 a year, unemployment averages 40% overall and the 500,000 Federally recognized Indians (representing over 260 tribes and 215 Alaskan Native villages) are spread very thinly over 26 States whose Indian populations vary from over 435 in Louisiana to 180,000 in Oklahoma. Partly due to these conditions, many diseases of potentially handicapping effect are extremely prevalent in the Indian populations; tuberculosis, for example, is 6.5 times higher than the rate for all of the citizens of the Uniited States. The increased prevalence of ear disease has already been mentioned. Not included in the present report, however, had been such other factors as the extremely high rate of persons crippled in automobile and other accidents, effects of other debilitating diseases that are not seen elsewhere in the United States (such as trachoma), and the whole gamut of conditions arising from poor nutrition, etc.

With respect too the concerns of this Conference, the primary need for assessment of handicapping conditions, persons affected by these conditions, services available, and services needed must first start with developing cross cultural definitions of what constitutes a handicap, how persons with handicapping conditions can be located in view of some of the problems mentioned above, determning which of these conditions might eventually be preventable and an assessment of rehabilitation program needs of those whom the condition already exists.

During the first four years of a comprehensive otitis media control program initiated by the Indian Health Service in 1970 a total of 125,000 persons were screened of which 32,000 failed one or more screening tests. From this number, 16,500 were found to have a loss of hearing in one or both ears. During the same time period, 8,000 persons received surgical procedures. Assuming an 80% audiometric success rate, this would leave a reservoir of 10,500 persons (mostly children) to have been found to have a hearing loss which would be considered at least mildly handicapping. The overall estimate of persons potentially benefiting from the use of a hearing aid in Indian Health Service is 12,5000 at the present time.

HISTORICAL PERSPECTIVE

The extent of handicapping conditions in previous times and their prevalence among American Indian groups can only be surmised. One way of determining whether or not such conditions existed is to determine from the native language whether or not words in that language exist for a particular problem. Again very few linguists have written on this matter nor, to the writer's knowledge, has anyone interested in handicapping conditions investigated the linguistics literature to determine the existence of such conditions. One notable exception to this was the work done by Sapir (1915) whose study of "abnormal speech Nootka" developed the interesting thesis that certain consonants in the Nootka language had linguistic meaning and designated certain physical classes of persons such as unusually fat people, unusually short adults, those suffering from visual defects, hunchbacks, etc. Particularly prevalent were a wide variety of speech defects expressed through such "consonatal play." Other than these references, however, no other reference to handicapping conditons historically were located by this writer.

STATE OF THE ART

As can be inferred from the foregoing, the "art" of determining the extent and severity of handicapping conditions among the American Indian and Alaskan Native peoples is by all accounts extremely primitive at the present time. Existing health records are not designed to extract information regarding handicapping conditions per se nor is there a strong liklihood that such categories would be included in the near future. Other sources of information such as State registers for handicapped children, vocational rehabilitation programs, and other sources from State and Federal agencies, are increasingly difficult to come by for a number of reasons such as the fact that no racial identification of the handicapped person is recorded, the Privacy Act, etc. Many Indian groups today are still very highly mobile and individual persons may seek out services from any number of different facilities within a large geographic area so that even if a handicapping condition were to be noted there is a liklihood that it would be recorded several times. This is further complicated by the tendancy among some Indian groups for persons to change their names with some regularity so that even reliable census figures are not obtainable at the present time in many of the locales served by Indian Health

Service. "State of the art" at this time is a rather vague concept in the context of the needs of this White House Conference.

BIBLIOGRAPHY

R. L. Bergman, M.D. "Boarding Schools and Psychological Problems of Indian Children," reprinted in *Hearing Before the Special Subcommittee on Indian Education of the Committee on Labor and Public Welfare U.S. Senate* Part 3, 1968, Pages 1121-1127.

J.F. Bryde, S.J., Ph.D., prepared statement in *Hearings Before the Special Subcommittee on Indian Education of the Committee on Labor and Public Welfare U.S. Senate* Part 1, 1967.

Wm. Carlile, M.D., personal communication, March, 1976.

K.W. Deuschle, M.D., prepared statement in *Hearings Before the Subcommittee on Indian Education of the Committee on Labor and Public Welfare U.S. Senate* Part 1, 1969, Pages 537-553.

K.L. Fleshman, M.D., prepared statement in *Hearing Before the Subcommittee on Indian Education of the Committee on Labor and Public Welfare U.S. Senate* Part 1, 1969, Pages 537-553.

K.L. Fleshman, M.D., prepared statement in *Hearings Before the Subcommittee on Indian Education of the Committee on Labor and Public Welfare U.S. Senate* Part 1, 1969, Pages 529-5311.

Nachmann, Ph.D., prepared statement in *Hearings Before the Subcommittee on Indian Education of the Committee on Labor and Public Welfare U.S. Senate* Part 1, 1969, Pages 498-533.

E. Sapir, "Abnormal Types of speech in Nootka," reprinted in *Selected Writings of Edwards Sapir in Language, Culture, and Personality,* (Ed.) David G. Mandebaum, University of California Press, Brooklyn Los Angeles, 1951: Pages 179-196.

J. L. Stewart, "Provision of Health Care of Underserved Populations," *Volta Review,* January 1975, Pages 64-71.

SECTION IV
UNIQUE PROBLEMS OF HANDICAPPED INDIVIDUALS WITH SPANISH SURNAMES

INTRODUCTION

This paper intends to deal with the concerns of the Spanish speaking Americans and particulary with those within that community who experience handicaps. An effort will be made to present material that will be helpful in understanding this group of people, and to examine issues relative to the service delivery systems intended to meet their needs. There will be an attempt to describe the Spanish speaking population, including: an assessment of their numbers, their mode of entry, their relative position in this society, and the causes of their disproportionate socio/economic problems. An effort will also be made to illustrate the unique cultural differences that have an impact upon the therapeutic or rehabilitation efforts made in their behalf. Finally to be considered are those issues involving the effectiveness or ineffectiveness of the socio / medical / educational / rehabilitation systems that have been established to serve the needs of the handicapped. This will include alternative strategies or approaches that merit examination/implementation/evaluation.

It is still recognized that the number of Spanish speaking persons in the United States comprises a substantial population, enough to form the fourth largest Spanish speaking country in the Americans after Mexico, Argentina, and Columbia. While historically they have been identified with the southwest, they are also found in significant numbers throughout the U.S. They represent 17 percent of the population of California, 30 percent of New Mexico, 20 percent of Colorado and great numbers in other states such as Washington, Michigan, Illinois, Kansas, and Iowa. The Los Angeles area has approximately 1.5 million persons of Spanish speaking descent, making it one of the largest Spanish speaking cities in the world (Burns, 1972). There are approximately 3.5 million persons of Puerto Rican descent, and one million of these reside in New York, and there are great populatons in New Jersey, Massachusetts, Pennsylvania, and Florida, as well as

many states throughout the nation. Persons from virtually every Spanish speaking country can be found in the United States. These include the Cubans in Dade County, Florida and persons from other Carribbean, Central, and South American countries.

All Spanish speaking people have concerns as an ethnic group in the United States, and these express themselves symptomatically in personal/socio/economic areas. Unfortunately, a large number (25 percent) are below the poverty level, 15 percent are unemployed and the dropout rate from school ranges from 50 to 80 percent with educational under-achievement being a universal concern (Padilla and Ruiz, 1973). As with other poor people, there is a high level of health problems and these are compounded by problems of malnutrition, industrial accidents, congenital defects, etc. Therefore, a higher incidence of handicapping conditions can be expected. These problems are then again compounded by a lack of resources to intervene in these conditions. There is also the problem of a lack of responsiveness by social/medical/manpower/educational/rehabilitation delivery systems.

HISTORICAL PERSPECTIVE

The Spanish-speaking has played a significant role in this country beginning with Columbus in 1492 when he was involved in the "discovery" of America. Very little information is available to indicate the extent of handicapping conditions of this particular group of people. They have, however been continuously entering since that time.

Immigration to the U.S. from Mexico was at its peak at the turn of the century during the Mexican Revolution as people sought refuge here. World War I created a ready labor market for them and thus number of Spanish speaking people increased dramatically. Since then the stream has continued, not only from Mexico but from virtually every Spanish speaking country. Puerto Ricans are U.S. citizens, and they have also come to the mainland in great numbers.

These newcomers have been added to the existing pool of stagnation, and this condition of colonization seems to continue to apply to the entire Spanish speaking population, whether they have been Americans for three or three hundred years. This condition within the country is often referred to as 'Internal Colonialism'. Nevertheless, despite any mode of entry the conditions of external control and powerlessness, disenfranchisement and racism continue.

The Spanish speaking people have very little to say about, or opportunity to share in the responsibility for the decisions in those matters that effect them. They are seldom found in policy making, administration or professional positions. The agencies providing those services are often homogeneous in the composition of their personnel to the extent that input for the culturally different is non-existent.

Consequently, it may be expected that those agencies are neither sensitive nor responsive to their concerns and are lacking in a reflection of their culture. Without this a revitalization of that culture is not possible; which impossibility further perpetuates the people's oppression. Under these circumstances a situation exists where the people endeavor to accomodate themselves to their environment in vain. The service agencies do not try to respond to their clientele. In summary then, it can be concluded that the problems of people in certain groups, such as the minorities of the Spanish speaking people in the U.S., are a result of external or environmental conditions, and not the result of the innate deficiencies of their culture.

Therefore, the issue is this: a delivery system with integrity must address itself to the unique cultural differences of the handicapped among the Spanish speaking people, or it will force them to surrender their integrity. It is not realistic to seek changes without a willingness to make positive changes to accomodate the vital needs of others. However, resistance to change is inherent in organizations; since in time they have become closed, professional, self serving and self perpetuating. This, then, is a serious challenge; these changes may only occur if given the attention of concerned movements; such as The White House Conference on the Handicapped. While the dynamics illustrated herein are those of the Spanish speaking, they may be equally applicable for all groups of the handicapped.

CULTURAL CHARACTERISTICS OF THE SPANISH SPEAKING

There are unique cultural characteristics extant among the Spanish speaking that must be considered when working with their disabled.

First, the family is considered as the most important social unit, and individual interests or aspirations are subordinate to those of the family. Each member has a unique and responsible role with the father being the head and responsible for providing for his family as well for their behavior in and out of the home. He has a great degree of freedom, and needs to practice his machismo which is done in a strict but gentle manner. The mother devotes herself to her husband and children with her personal interests secondary to those. She has the greatest influence in the family but exercises it in subtle ways. The children are treasured and indulged with great amounts of personal and physical affection. They are not without responsibility however, and this may take precedence over school or personal attainment. When a disabling condition interrupts this system, it may create a serious crisis; e.g., if the father cannot continue in his role of provider he may be personally devastated particularly if the mother must go to work. His machismo may not allow him to do 'womanly' chores and thus role changes are difficult. He might turn to alcohol and children may not sustain the traditional levels of respect under such conditions. Thus the traditional cultural strengths may not be operable. On the other hand, inasmuch as a cultural characteristic of the Spanish speaking is what is described as a cooperative society, it can be utilized as an intervening variable to compensate for the losses due to disability and thus maintain the strengths of the family unit.

The Spanish speaking traditionally have practiced folk medicine and may only seek clinical services on a crisis basis. thus unresponsive therapeutic efforts might be considered with suspicion and home remedies used to the extent that access to proven rehabilitation measures might be delayed. This argues for understanding and responsive programs.

CULTURAL SHOCK AND SOCIAL SERVICES

Ethnic minorities share in the right to have their values and ways of life respected and incorporated into institutional and social service programs—rehabilitation services being only one of the multifaceted services available in our communities. No man develops by himself, rather he is a product of the socialization and enculturation. Inherent is the understanding that there are significant differences in the ways cultural groups define problems, participate in planning interventions, and utilize systems available to deal with problems that may arise. The individual must be viewed from a vantage point that incorporates the client's values, family structure and community matrix and not merely the medical aspects of the disability. The challenge then for those working with the Spanish disabled is to give consideration to the distinctive socio-cultural attributes within the client's community matrix.

Physical and mental disabilities are a part of life, yet their psychological consequences are monumental. The individual experiences a sense of powerlessness and loneliness, avoidance and denial, hostility and anger. The physical trauma of loss generates a series of phenomena-denial and isolation, anger and hostility, depression and resolution—which demands a process of adjustment by the individual. Though change is a characteristic of life, in the dominant society's view, change involves mastery and control over the environment in a manner that subsumes achievement.

The adaptive style of the individual is directly related to the degree to which the individual ascribes to a particular set of cultural characteristics. The systematic body of learned characteristics, which are transmitted from parent to child, can be regarded as being on a continuum; that is a flow binding one generation to another. Thus, members from a Spanish speaking cultural experience and percepition have a greater liklihood of ascribing to these behavioral characteristics than their Anglo counterparts (Murillo, 1971). The behaviors noted along the continuum range from a more traditional to an assimilative perspective. Often in clinical settings, evaluations are based in terms of the Spanish speaking individual's degree of adjustment to the majority culture. It is well to note that the same behaviors have different meanings for different cultural groups.

Deviance from the expected norm does not necessarily denote pathology, but rather reflects a dynamic process in which members are continually adjusting their patterns of living and ways of coping. The primary goal of the counselor thus is to assist the handicapped or disabled individual in achieving a lifestyle which is satisfying and congruent with his self-perception.

Cultural perspectives do influence the adaptive process; in this case, defined as the dynamic process of reciprocal interaction between man and his environment, to achieve a sense of equilibrium. The Spanish speaking individual, who is psychologically prone to accept support and cooperation, finds himself in conflict when placed in a treatment plan that emphasizes self-reliance and individualism. Generally solutions and roles for the individual in accordance with his abilities and capabilities. The individual's The Spanish speaking community provides an avenue for acceptance by altering the expectations and roles for the individual in accord with his abilities and capabilities. The individual's status, acceptance, and prestige is still based on the handicapped/disabled individual's ability to assume those altered roles and responsibilities which contribute toward the common good of the household. Though his accommodation retains the individual's dignity, status and prestige, it may deter from that individual's utilization of services. The potential fear of being lost, or disregarded by social/medical/rehabilitation service agencies, overrides the necessity of those services.

In contrast, the individual's acceptance in the dominant society is related to or measured by the individual's ability to succeed and climb the ladder of success. Emphasis is given to individualistic, aggressive, and competitive roles in both seeking assistance from social service agencies and in cooperating with the treatment of rehabilitative plan. Institutions often define the client's ability to relate successfully with the particular agency in terms of "motivation."

In addition to the complementary role conflict, the Spanish speaking individual finds that the clinical agencies are often unable to meet the client at the level of his psychological readiness for interdependence, because the term denotes a negative rather than a positive connotation. Interdependence can be viewed as a tool for growth from which the individual emerges with the skills and tools to achieve a lifestyle that is satisfying and congruent with his self perception.

One major point this paper has continually attempted to make clear is this: the Spanish speaking people have been barred from an active role in the administration of the helping services designed to alleviate their disadvantaged socio-economic position. Because little input has been allowed from this group, they have been disenfranchised from the decision-making processes that govern their lives. They have suffered from a lack of responsiveness to their unique cultural characteristics, which has been symptomatic of the service organizations created to serve the handicapped individuals of our society. It has been established that the environment in which they exist, which can justly be described as colonialism, has been the major cause generally of their disadvantaged socio-economic position.

This is the vicious cycle of poverty. If we are to enable these people to share in the services provided for them, alternative strategies must be examined. The consideration and possible acceptance of these new directions is more than a challenge; it is, and must be, a legitimate public issue.

Therefore, sheer economics support the need for responsive service and make is feasible to create separate programs for each ethnic group. It would seem that, where there is a critical need to justify it, community based programs should be preferred, and that under such conditions a separatist strategy would be a rational choice. Its strength is that it places responsibility and accountability closer to the client and, therefore, closer to the problems. Further, it permits self-determination and decreases the dependence upon external administration, which has often been insensitive or paternalistic.

A serious effort is required to eliminate the artificial barriers that have kept them out. The selection criteria for positions in those agencies serving the handicapped must reflect and accept the cultural characteristics of all applicants. This strategy may be described as one of cultural pluralism. Its consideration is a major issue; it has neither been accepted nor practiced before. It is also a strategy which will be welcomed by the Spanish speaking community.

RECOMMENDATIONS

The following are suggested recommendation for consideration by the White House Conference on Handicapped Individuals:

1. To insist on the inclusion of the Spanish speaking community in all programs for the handicapped by the establishment of mechanisms that ensure meaningful input from them, and participation by them in those programs that affect them.

2. To insist on enforcable affirmative action programs that institutionalize the involvement of the Spanish speaking people at all levels of the organizational hierarchy of those programs and agencies that serve the handicapped.

3. To provide for research and demonstration projects that explore effective means by which to serve the handicapped Spanish speaking in a manner utilizing the strengths of their culture.

4. To promote cultural awareness training that promotes understanding acceptance and respect for all persons regardless of race or sex.

BIBLIOGRAPHY

Adler, Peter. "The Transitional Experience: An Alternative Niew of Culture Schock," *Journal of Humanistic Psychology,* Vol. 15, No. 4, Fall, 1975.

Arma, Jose, Editor. *De Colores Journal of Emergine Raza Philosophies,* Vol 2, No. 2, 1975.

Blauner, Robert. "Internal Colonialism and Ghetto Revolt," *Social Problems*, 1968.

Burns, E. Gradford. *Latin America, A Concise Interpretive History.* New Jersey: Prentice Hall, 1972.

Gonzales, Rodolfo. *I Am Joaquin.* New York: Bantam Books, Inc., 1972.

Hays, Dorothea, "Teaching a Concept of Anxiety," 1961.

Lee, Jane M. "Emotional Reactions to Traume," *Nursing Clinics of North America.* Vol. 5, No. 4, December, 1970.

Murillo, Nathan. The Mexican American Family. In: Wagner, Nathaniel N., and Haug, Marsha J., eds. *Chicanos: Social and Psychological* Perspectives. Saint Louis: C.V. Mosby Company, 1971.

Padilla, Amado M. and Ruiz, Rene A. *Latino Mental Health A Review of Literature.* Washington, D.C.: U.S. Government Printing Office, 1973.

Paz, Octavio. *The Labyrinth of Solitude.* translated by Lysander Kemp. New York: Grove Press, Inc., 1961.

Roberts, Sharon. *Behavioral Concepts and the Critically Ill Patient.* New Jersey: Prentice Hall, Inc., 1976.

Sapir, Edward. *Culture, Language and Personality.* Berkeley: University of California Press, 1964.

Sarbin, Theodore. "Culture, Social Identity and Cognitive Outcomes," *Psychological Factors in Poverty,* ed. Vernon L. Allen. Chicano: Markham Publishing Co.

UNIQUE PROBLEMS OF DISABLED VETERANS

Awareness Paper Prepared By

James A. Maye
Paralyzed Veterans of America
Washington, D.C.

TABLE OF CONTENTS

	Page
Introduction	451
Definition of Terms	451
Historical Perspective	451
A Profile of the Veteran Population	452
A Profile of the "Typical" Veteran	453
Profile of a Disabled Veteran	453
The Unique Area	453
Conclusions	454
Recommendations	455
References	456

INTRODUCTION

The purpose of this paper is to incite discussion and further research into the unique problems of disabled veterans. Generally speaking, one could initially assess the problems facing the disabled veteran and the civilian disabled as being the same. In part, this is true, for such things as architectural barriers, social attitudes, and scientific technology affect all similar types of disability groups equally. Usage of the term "unique" in dealing with veteran's problems can be justified in two general areas: (1) Because the Federal and State governments have established a separate system with specific methods to deal with disabled veterans, the effects of these programs, both good and bad, are unique to the veteran population; (2) When the disabled veteran population is viewed collectively, certain problems have significantly different occurrences than are found in the civilian disabled population. These problems are considered to be unique to disabled veterans and will be the subjects of discussion of this background paper.

The scope of this paper will be limited to those areas considered to be of a problem nature to the disabled veteran and unique because of the manner in which it is dealt with or because of the nature of the group in which the problem occurs.

DEFINITION OF TERMS

The term "disabled veteran" may conjure up emotional images of limbless, blind, or otherwise crippled young men. It is not very definitive for purposes of describing those persons eligible for federally funded veteran's programs. Title 38 of the U.S. Code defines a veteran as a person who has served a minimum of "181 days of military service" in an "active duty" status before release from one of the Armed Services. Further eligibility requirements for "disabled veteran" status take into consideration the category of discharge which the individual received, the dates of his period of service, his physical and mental state, and even his financial status. In order to better understand the term "disabled veteran" it is necessary to take these and other conditions into account and establish two definite groups. Assuming that the individual has met the requirements for minimum service, has an "honorable" discharge, and is physically, mentally, or emotionally impaired to some degree, he will fall into one of two groups. The first group would be those veterans with service connected disabilities, or, more clearly described, those veterans suffering from disabilities contracted during and/or directly related to their military service, and for which the Armed Service accepts responsibility. Examples of this would be the man who has lost a limb during military combat, the person injured in military exercises during a non-combat situation, or even the veteran who has suffered emotional or mental impairment because of the stressful nature of his military duty. In essence, any disability that can be proven to be directly related to military service constitutes a service connected disability.*

The second group of disabled veterans is composed of veterans with honorable discharges, whose disabilities are not related to military service. This group must again be sub-divided in order to understand the initial levels of eligibility for veteran's programs. The first subdivision of these non-service connected veterans consists of those whose period of military service coincided in whole or part with a period in which the United States was involved in a declared or an undeclared war. A person who was in the Armed Service on an Active Duty status during any period in which the U.S. was involved in a war would be classified as a "wartime non-service connected veteran provided he meets the other disability requirements. For those whose military service fell into those periods between wars, the classification would be "peace-time non-service connected veteran."

For the remainder of this paper, the various groups of disabled veterans will be referred to as "service connected," "non-service connected wartime," or "non-service connected peacetime."

HISTORICAL PERSPECTIVE

In this nation's two hundred years history, it has been involved in numerous wars, both large and small. In each war's aftermath, there have been many wounded soldiers who bore the weight of battle in defense of the country, its

*There are certain other limited circumstances in which a disability can be classified as a service connected disability even though the specific disability did not occur in the period of military service.

people, and its ideals. Historically the citizens of this nation have paid reparation to these disabled veterans in many forms. The first type of compensation came in the form of small community operated Veterans' Homes and local or state sponsored pensions. In 1917 the Congress of the United States passed Public Law 65-90 providing medical care for those veterans of World War I who had suffered disabling injuries as a direct result of the war. Three years later, the Veterans Bureau was established and by executive order of the President of the United States, a number of Public Health Service Hospitals were transferred to the Bureau for the exclusive purpose of treating disabled veterans with service connected disabilities.[1]

In 1930 the Veterans Bureau became the Veterans Administration and was charged with the responsibility of caring for veterans of all wars. In 1934 a major revision was made and the V.A. began caring for the non-service connected veteran also, provided that the individual was without financial resources to pay for care in a civilian hospital.[2]

At the conclusion of World War II, the Congress charged the Veterans Administration with the administration of a monetary compensation to those veterans with residual disabilities resulting from service connected causes. The end of the Korean War saw further advances in compensation and in rehabilitation and pension programs for both service connected and non-service connected wartime veterans. Those World War II and Korean War programs included the GI Bill of Rights for furthering education and technical training. Chapter 31 of Title 38 provided for vocational rehabilitation to service connected veterans and for an income supplement to 100% disabled non-service connected veterans, in the form of a disability pension. Over the years the programs of the V.A. have grown and modified to meet the needs of all veterans with the first priority for services going to the service connected veteran. The history of the V.A. and its programs is reflective of the wishes of the American citizen to meet his obligation to those who defended him and his family and the desire to restore each individual to his full potential.

Today the V.A. operates 171 hospitals, 213 outpatient clinics, 85 nursing homes, 18 domiciliaries, 128 mental hygiene clinics, 55 day treatment centers, 43 day hospitals, 71 alcohol dependence units, and 53 drug treatment centers.[3]

A PROFILE OF THE VETERAN POPULATION

The population of veterans in this country accounts for one of our largest minorities. The 1975 V.A. census indicated that there are 29,294,000 veterans, of which 26,194,000 have had some period of wartime service. The number of disabled veterans totaled 3,226,296 and was composed of 2,220,169 with service connected disabilities and 1,006,127 with non-service connected wartime disabilities. It should be noted that there are no statistics on the number of non-service connected peace-time disabilities because the Veterans Administration does not have access to information on disabilities unless a claim for V.A. benefits is filed. No monetary benefit programs are available for this category.

In the category of non-service connected wartime, it is somewhat difficult to ascertain the severity of disabilities and it is not wise to place very much faith in these figures as being representative of the actual number of veterans with disabilities. The reason for this is that a financial need criterion is placed upon eligibility for receipt of any benefits and the records reflect only those persons in receipt of pensions from the V.A. Conversely, the V.A. places no financial need requirement upon the service connected veteran, for his benefits are a payment of due compensation for losses incurred in line of duty. Furthermore, in the case of the service connected veteran, the V.A. medical review rates the degree of disability. The rating scale is from 0% to 100% in ten percent increments. The degrees of impairment and the percentages of service connected veterans with those degrees of impairment are shown in the following table.

	Number	*Percent of Total*
No disability	28,765	1.3
10%	867,866	39.1
20%	344,756	15.5
30%	315,208	14.2
40%	180,626	8.1
50%	112,573	5.1
60%	117,217	5.3
70%	78,394	3.5
80%	38,154	1.7
90%	13,215	0.6
100%	123,395	5.6
Total	2,220,169	100.0

It is also interesting to note that 422,536 of the service connected veterans are from the Viet Nam Era. The number of non-service connected wartime veterans from the Viet Nam Era is 7,299.

PROFILE OF THE "TYPICAL" VETERAN

In order to support the premise of the unique nature of veterans' problems, it is necessary to determine how the "typical" veteran differs from his non-veteran contemporaries.

1. A combination of stringent medical screening prior to entry into the military service, the provision of excellent health care by the Armed Services, and the active physical nature of the military life style results in an individual physically stronger and healthier than the national average.
2. The ratio of males to females among veterans is drastically different from the civilian sector. In 1975 there were a total of 562,000 female veterans in the United States, or approximately 1.3% of the total veteran population.
3. The mean average education of the veteran population is 12.6 years; it is 12.3 years for the non-veteran male population.
4. The mean average income for veterans is $11,360 per year; for non-veterans, it is $7,430 per year.
5. The unemployment rate for veterans in 1975 was 4.7%, while for non-veterans it was 8.3%.

The profile developed from the above statistics shows the typical veteran to be a male, most probably the head of a household, above average in health, annual income, employment, and slightly better educated than his contemporaries. It would be reasonable to assume that in the case of the disabled veteran, this profile would be similar if it were not for the intervention of his disability.

PROFILE OF A DISABLED VETERAN

Examination of statistics concerning disabled veterans reveals the following:

1. Health variable, from good to poor with the probable average just below that of the general population.
2. The ratio of males to females among the disabled veteran population is even greater than for the overall veteran population. Less than 0.5% of disabled veterans are female.*
3. The average educational level of disabled veterans is comparable to that of the total veteran population at 12.6 years.
4. The mean average income would seem to be substantially below that of the average veteran, although this cannot be completely substantiated. A survey of spinal cord injured veterans indicated an annual income of approximately $7,200 per year.
5. Unemployment for the disabled veteran is significantly greater than for the total veteran population and than the non-veteran able-bodied population. The unemployment percentages vary with the categories of disability. The HumRRo report indicated percentages as low as 8% for the college graduate with a minor disability and as high as 30% for the high school dropout with a severe disability. Other statistics provided by the Paralyzed Veterans of America indicate that unemployment among paralyzed veterans is as high as 87%.

Thus, the profile of the "typical" disabled veteran is that of a male of less than average health, having a high school diploma, earning less than his physically fit veteran contemporaries and slightly less than the average non-veteran male, and having moderate to severe difficulty in finding employment.

THE UNIQUE AREAS

It is necessary to make a distinction between the different groups of disabled veterans. In order to see how the problems of the disabled veterans are uniquely different from the problems of the disabled civilian population. The group having the fewest number of differences in problems when compared to the civilian disabled would be the non-service connected peacetime veteran, followed by the non-service connected wartime veteran, and finally the service connected veteran, who shows the greatest variance in problem areas.

*Estimate based on V.A. figures and polls of several veterans' organizations including Paralyzed Veterans of America, Blinded Veterans and Disabled American Veterans.

Both non-service and service connected veterans differ from their civilian counterparts in the following ways:

1. Extremely high ratio of males to females.
2. The availability of separate medical facilities in Veterans Administration Hospitals at no cost to the veteran.
3. Certain educational benefits such as the G.I. Bill.
4. Eligibility for membership in certain veterans' organizations which can assist him in receiving his lawful veteran's benefits.
5. Nearly all are in the age groups which are normally employed.

The non-service connected wartime veteran has, in addition to the above, other available programs:

1. The availability of a Veteran's Pension Program which is based on financial need. This income supplement is designed to provide those with the greatest need a modest financial base on which to live. As their income increases, the financial assistance diminishes proportionally.
2. In conjunction with the Pension Program, certain limited medications and prosthetics are available to the non-service connected wartime veteran, provided his income does not exceed a certain level.

Program differences and also variances in group profile are most evident when the service connected veteran is compared with the civilian sector of the disabled population:

1. The service connected veteran is more likely to have enjoyed excellent physical health prior to a sudden and traumatic onset of his disability. There will be an exclusion of such factors as serious congenital defects, crippling childhood diseases, and disorders related to aging.
2. The effects of the disability create situations in which the individual is mandatorally removed from his job and his life style, i.e., the military service. In all cases he must find re-employment and a new life style. Although this may be true in the civilian sector, in many cases the disabled individual can and does return to the same job or to the same type of work.
3. The service delivery systems for veterans programs work both for and against disabled veterans. For example, both state and local programs for the disabled encourage if not require the disabled veteran to utilize his V.A. benefits before he is eligible for their programs. The Veterans Administration provides for such services as physical restoration, rehabilitation, and education to disabled veterans but it does not operate its own program for job placement. The veteran is usually left to seek such services from other agencies or to find employment on his own. The HumRRo study indicated that 70% of the veterans in their study had to seek employment without assistance. Ineffectual programs in veterans employment do a major disservice to him. One Labor Department program is reported to have placed only 22.7% of the two million veterans who sought its services. Only half of those two million veterans received any reportable service at all. Only 16.7% of the disabled veterans seeking assistance were employed.[13] This differs from the services provided by the various states' Departments of Vocational Rehabilitation where the policy is to assist the individual through the entire physical restoration, training, job placement, and follow up which insures readjustment by the client.

For all practical purposes, the disabled service connected veteran can be viewed as having the same potentials as those characteristics given for all veterans, but investigation bears out the supposition that most disabled veterans are underemployed relative to their capabilities and in comparison to their able-bodied counterparts.

There are still other areas of special concern which affect the veteran differently from the non-veteran. Some of these, such as public attitudes towards veterans of the Viet Nam Era are difficult to document. However, without doubt, many of these veterans suffer additional prejudices because of their participation in an unpopular war, misconceptions of war atrocities, and the prevalent use of drugs. These have created problems which are unique to Viet Nam Era veterans.

CONCLUSIONS

Certain data have been presented in this paper to support the supposition that disabled veterans as a group are unique in certain circumstances, and that problems arising from these situations

are peculiar to that specific group. As a result of the research for this paper, five significant problem areas unqiue to disabled veterans became apparent:

Problem I: In the case of the veteran with the service connected disability, current military procedures necessitate the abrupt conclusion to his employment and retraining and relocation under a new employer. This is true for all cases of service connected veterans. The disabled civilian may have the opportunity to return to the same employer, either through modification of his old job or through a change of position after retraining.

Problem II: Veterans with non-service connected disabilities who qualify with wartime service are penalized when they return to gainful employment by having their meager veteran's pension and medical and prosthetic benefits drastically reduced or more probably stopped. Such negative incentives cannot help but influence the seriously disabled veteran who already has mental reservations about his ability to function in a competitive setting to avoid the risk of giving up the limited security of a guaranteed pension for a job which he may not be able to perform. With the exception of welfare programs, the civilian does not face this degree of negative incentive.

Problem III: Certain problems are inherent in the programs set up for disabled veterans by the Federal Government. Although these problems are numerous, one is of paramount importance. The rehabilitative service offered by the Veterans Administration includes physical restoration, provision of basic prosthetics, retraining, and possible provision of limited tools for employment, but no job placement service or vocational follow-up is offered which can be comparable to those services offered by the State Vocational Rehabilitation Programs. The veteran is left on his own to locate and contact other appropriate Federal agencies responsible for assisting him with employment. The result is very poor coordination between agencies who are supposed to work together for the total rehabilitation effort. Those agencies charged with the duties of finding employment for the veteran fail to do an adequate job. The greater percentage of disabled veterans are left to find employment without any agency assistance. The lack of follow-up procedures further complicates situations because programs can seldom be evaluated for proficiency or effectiveness.

Problem IV: In many states and localities there are regulations which restrict dual eligibility for rehabilitation benefits. The disabled veteran is restricted from utilizing state and local programs which may be superior to Federal benefits until those Federal benefits have expired or have been exhausted. Without question, having access to two different programs is much better than having access to only one as is the case for the civilian disabled, but a unique problem develops for the veteran in that cooperative agreements between separate Federal and State or local programs seldom occur and the veteran is not counseled as to the comparative value of different programs. The result is a loss of energy, time, and money, while the veteran tries to make an educated guess as to the appropriate action.

Problem V: An unusual turn of events in our history of national policy has created a nationwide review of ethics. The intervention of the United States in the internal affairs of Viet Nam caused great social upheaval in America and without doubt the Viet Nam Era veteran has suffered from the stigma attached to that war. For veterans who became disabled in that conflict, an added barrier comes between him and the general public. It is a well accepted fact that the public has emotional reservations about dealing with any physically, emotionally, or mentally impaired individual. So the Viet Nam Era disabled veteran has even more prejudices to overcome, because of the time and place in which he became disabled.

RECOMMENDATIONS

It is the recommendation of this paper that a more in-depth study to be undertaken to identify other problems which are unique to the disabled veteran population. They must be identified in order to initiate a plan of action for their resolution and to bring the goal of total rehabilitation one step closer.

A second recommendation is that because of the generally good educational, financial, and organizational levels which disabled veterans have already attained, the resources which they can contribute must be utilized more fully in order to benefit all disabled individuals. The

White House Conference on Handicapped Individuals and other civilian disability groups should begin investigation into areas of similar interests and needs and develop programs in cooperation with and with the assistance of veterans groups such as the Disabled American Veterans, the Blinded Veterans Association, and the Paralyzed Veterans of America.

REFERENCES

1. Report of a Special Survey of the Level and the Quality of Patient Care at Veterans Administration Hospitals and Clinics, July 31, 1974, Directed by the President March 31, 1974, Veterans Administration, Department of Medicine and Surgery, Washington, D.C.
2. V.A. Special Survey, *Ibid.*
3. White House Conference on Handicapped Individuals, Background Issue Paper on the Unique Problems Faced by Veterans, Charles A. Stenger, Ph.D. and Cecil P. Peck, Ph.D., 1976, Veterans Administration, Washington, D.C.
4. 1974 Annual Report of the Veterans Administration, Washington, D.C.
5. V.A. Annual Report, *Ibid.*
6. V.A. Annual Report, *Ibid.*
7. V.A. Annual Report, *Ibid.*
8. V.A. Annual Report, *Ibid.*
9. V.A. Annual Report, *Ibid.*
10. V.A. Annual Report, *Ibid.*
11. V.A. Annual Report, *Ibid.*
12. Paralyzed Veterans of America, Survey of the Economic Needs of the Paralyzed Veteran, Nov. 1975, Washington, D.C.
13. Opening statement of Senator Vance Hartke, Chairman of the Senate Committee on Veterans' Affairs, before the subcommittee on Readjustment, Education, and Employment, October 22, 1975.

UNIQUE PROBLEMS OF THE HANDICAPPED AGING

Awareness Paper Prepared By

Dolores A. Davis, Ph.D.
and
Obidima I. Onyemelukwe, M.A.
National Center on the Black Aged, Inc.
Washington, D.C.

TABLE OF CONTENTS

Page

Introduction 459

The Growth of the Aged and the Handicapped Aged in the Population 459

The Place of the Handicapped Elderly in Federal Programs Benefiting the Elderly 461

- Employment 461
- Health Care 462
- Housing 463
- Income Maintenance 463

Search for Solutions 464

Summary 465

References 465

Selected Bibliography 466

Tables . . . . .

- Table 1 Normal Retirement Age of Men 459
- Table 2 Normal Retirement Age of Women 460
- Table 3 Number and Percentage of Older Americans 460
- Table 4 Growth Rate of Total Population and the Elderly 461
- Table 5 Percentage with a Specified Number of Chronic Conditions 461
- Table 6 Impairments Due to Injury Per 1000 Population by Age 462
- Table 7 Elderly: Proportion with Incomes from Specified Sources, 1974 464

INTRODUCTION

This paper is addressed to the public policy issues facing the handicapped elderly. This group of the elderly is a minority within the population of the American elderly—a minority within a minority. The field of aging is briefly reviewed and the place of the handicapped elderly within the field is assessed. In particular, the treatment of the handicapped elderly in the Older Americans Act, and under Social Security, is appraised and recommendations are developed for legislative action, designed to maintain the income of this elderly population and assure them the *defined coverage* in all programs serving the elderly, especially in areas of income, health and housing.

The multi-dimensional and peculiar problems of the elderly handicapped relate to inequitable treatment of this group within the provisions of the Federal Housing Act; the implementation of health programs under the Social Security Act, (Medicare and Medicaid) and the structuring of major Federal income maintenance programs benefiting the elderly; the transportation programs of the Urban Mass Transportation Act; and the major training and research programs designed to provide manpower in the field of aging; major employment programs benefiting the elderly under various legislative actions such as the Domestic Volunteer Service Act and the Comprehensive Employment and Training Act. Although the legislation for many programs tend to refer to the "aged and the handicapped", the handicapped aged do not receive fair recognition in legislative programs or in the delivery of services. Federal programs do not discriminate between the elderly (able-bodied) and the handicapped elderly, because legislation for the care of the elderly has not attempted to isolate the special problems within the elderly population which require special attention.

THE GROWTH OF THE AGED AND THE HANDICAPPED AGED IN THE POPULATION

There is a general consensus that old age is the last stage of human development, but there is little agreement as to the exact age at which this final state begins, or the actual physical signs that indicate its onset. This creates problems for legislative programs dealing with the elderly.

Although there are biological, psychological and social definitions of aging, statistical demarcations of old age have been adopted by the United States and other nations. According to statistical definition, certain ages have been selected as those at which old age begins for purposes of retirement and pensions. Tables 1 and 2 show the different ages of retirement by sex, adopted by selected countries of the world.

In the United States, age sixty-five (65) has been selected as the age of retirement.[1] Therefore, "Older Americans" refers to any American at 65 years of age or above, and age 55 is defined as the age of eligibility for full Social Security benefits. However, many older Americans are now electing to retire at sixty-two (62) with reduced benefits under provisions provided by the Amendments to the Social Security Act.

Only in the last few decades has the attention of the United States Government been directed toward the social, economic, political and scientific problems associated with the aged segment of the American population. Increased interest and concern is due to the fact that handicapped older Americans are becoming an increasingly large part of our population. Table 3 illustrates the increasing proportion and Table 4 the phenomenal growth rate of the elderly since 1900.

These figures provide an indication of the growth of the handicapped aged, in view of the

Table I. Normal Retirement Age of Men

70 Years	67 Years	65 Years	60 Years
Norway	Denmark	Canada	U.S.S.R.
Ireland	Sweden	Luxembourg	Czechoslavakia
	Iceland	United States	Japan
		Spain	Italy
		Portugal	Yugoslavia
		Netherlands	
		France	
		Finland	
		Switzerland	
		Israel	
		United Kingdom	
		W. Germany	
		Poland	
		Belgium	

Reconstructed from Table 9 of U.N., *Aging: Trends and Policies*, United Nations, New York, 1975, p. 73.

Table 2. Normal Retirement Age of Women

70 Years	67 Years	65 Years	60 Years	55 Years
Norway	Denmark	Canada	Israel	U.S.S.R.
Ireland	Sweden	Luxembourg	U. Kingdom	Czechoslavakia
	Ireland	United States	W. Germany	Japan
		Spain	Austria	Italy
		Portugal	Poland	Hungary
		Netherlands	Australia	Yugoslavia
		France	Belgium	
		Finland		

Reconstructed from Table 9 of U.N. *Aging: Trends and Policies*, United Nations, New York, 1975, p. 33.

Table 3. Number and Percentage of Older Americans

Year	Number	Percentage
2000*	30,600	11.7
1985*	26,659	11.4
1975*	22,33(	10.5
1970	20,066	9.9
1960	16,560	9.2
1950	12,295	8.1
1940	9,036	6.8
1930	6,644	5.4
1920	4,940	4.7
1910	3,954	4.3
1900	3,084	4.1

SOURCE: Bureau of the Census, U.S. Dept. of Commerce, *We The American Elderly*, June 1973, p. 4.

*Estimates supplied by the Congressional Research Service, Library of Congress

fact that this population comprises approximately thirty-five percent (35%) of the elderly population.[2] Increases in birth rates between the 1800's and 1920's, the post World War I flood of immigrants, and advances in medical science contributed to the growth in number of this group of elderly in the United States. On the basis of the death rates in 1973, average life expectancy at birth was seventy-one point three (71.3) years for Americans.[3]

In view of the fact that public policy does not pay attention to this group of special minority, official statistics, for example, are classified into the "aged, the blind, and the disabled". This classification is a demonstration of the official inability to distinguish between the aged in general and the approximately one-third (1/3) that is handicapped, and, therefore, the failure to address programs and projects to the special needs of the impaired elderly.

Disabilities of various forms are part of new roles which some older people are likely to experience. The various degrees of disabilities produce varying degrees of incapacitation and dependency. It is estimated that about thirty-five percent (35%) of Americans aged 65 and over have some disability serious enough to limit their capacity to work, keep house or engage in other major activities.[4] The importance of aging is the fact that as age increases, the probability of disease, illness, or disability increases. Table 5 shows that people aged 65 and over have more

Table 4. Growth Rate of Total Population and The Elderly

Decade	Percentage Increase of Population	Percentage Increase of Elderly
1974-2000*	23.9	40.3
1960-1970	13	21
1950-1960	19	35
1940-1950	14	36
1930-1940	7	36
1910-1920	15	25
1900-1910	21	28

SOURCE: Bureau of the Census, U.S. Dept. of Commerce, June 1973, p. 5.

*Estimates supplied by the Congressional Research Service, Library of Congress

Table 5. Percent with a Specified Number of Chronic Conditions (Including Chronic Diseases and Impairments), by Age, United States, 1957 to 1958

No. of Conditions	All Ages	Age under 15	Age 15-44	Age 45-64	Age 65 +
Males:					
1 or more chronic conditions	39	19	39	58	75
Only 1 chronic condition	23	15	26	30	26
2 chronic conditions	9	3	9	16	21
3 or more chronic conditions	7	1	4	12	28
Females:					
1 or more chronic conditions	44	16	45	63	81
Only 1 chronic condition	23	13	26	27	27
2 chronic conditions	11	2	11	18	20
3 or more chronic conditions	10	1	8	18	34

SOURCE: United States National Health Survey, 1959 "Health Statistics." Series B., No. 11, p. 2.

chronic conditions at almost twice the rate of those aged fifteen through forty-four (15-44). A good number of the aged become handicapped because of injury. Table 6 gives a breakdown of impairment resulting from injury by age groups, and the elderly population leads the rest of the population in virtually all categories.

THE PLACE OF THE HANDICAPPED ELDERLY IN FEDERAL PROGRAMS BENEFITING THE ELDERLY

Historically, the impaired elderly have not been distinguished, either in law or in literature, from the rest of the elderly population. Researchers, as well as legislators tend to ignore this sub-group of the elderly completely, or vaguely refer to the "aged and handicapped" citizens, generally. Although the probability of one form of handicap or the other increases with age, there are millions of aged Americans who are not handicapped. These able-bodied elderly take up more than their fair share in programs serving the elderly, compared to the imparied elderly.

Employment

The major employment programs benefiting the elderly include the following: Older

Table 6. Impairments Due to Injury Per 1000 Population by Age

Type of Impairment	All Ages	Under 45 Years	45-64 Years	65 Years and over
Visual	4.6	2.8	7.2	12.0
Hearing	4.7	2.7	9.4	8.5
Paralysis, complete or partial	0.8	0.5	1.5	
Absence of entire fingers or feet	3.7	1.8	6.8	10.7
Absence of major extremities	0.9	0.4	2.1	
Impairments[1] back or spine	15.4	11.0	27.7	21.2
Impairments[1] upper extremities and shoulder	8.4	5.7	14.3	15.2
Impairments[1] lower extremities and hip	13.6	8.6	21.0	34.1
Other Multiple Impairments[1] of limbs, back and trunk	3.8	2.3	7.3	7.4
All other impairments	6.2	3.8	12.1	10.5

[1]Except Absence of Paralysis

SOURCE: This Table was reconstructed from data provided in the Department of Health, Education & Welfare, *Impairments Due to Injury, United States–1971*, pp. 9-20.

Americans Community Employment Service Programs, Volunteers in Service to America (VISTA), Service Corp of Retired Executives and Retired Senior Volunteer Program. Apart from VISTA, under the provisions of the Domestic Volunteer Service Act of 1973, the major Federal employment programs benefiting the elderly do not carry any special consideration for the physically and mentally impaired elderly. These programs should be re-oriented to address themselves to the drastic problems of employment facing elderly handicapped persons.

Health Care

Maintenance of good physical and mental health is of major importance to all aging and aged Americans. However, many handicapped older Americans living on limited fixed incomes do not receive adequate medical care because of prohibitive medical costs and the lack of trained health personnel to serve them.

The 1971 White House Conference on Aging recommended that comprehensive health care should be available to all elderly Americans as a matter of right and entitlement. Health care for the aged should be an integral part of a co-ordinated system that provides a comprehensive delivery of health care services including long term care for the impaired elderly. The provisions of these legislative acts are so general that the handicapped who are in dire need of extra attention have not been provided for.

The elderly handicapped who are in need of nursing-home care face a variety of problems in the cost, quality and range of services available. Average nursing home charges are about six hundred dollars ($600) per month; while average social security benefits for a retired couple are about three hundred and twelve dollars ($312) per month. Limitations on medicare coverage of such services often leave either the aged patient or the medicaid program (Title XIX of the Social Security Act) as the only source of payment. The developing trend toward reclassifi-

cation of patients to lower levels of care (from skilled nursing-homes to homes providing less medical care), fostered by the requirements of the Social Security Amendments of 1972 (P.L. 92-603) may be resulting in patient transfers based on consideration of State costs rather than the patients' need for care. The lack of availability of suitable alternatives to long-term care, such as home health services, results in the handicapped elderly being institutionalized when they could be better cared for in their own homes.

Many bills have been introduced in Congress that would expand the medicare program, but they have not addressed the problem of making a distinction between the impaired elderly and the rest of the elderly population. A person who is aged and also impaired has special health problems which deserve special attention within already established health programs. The Program of Health Insurance for the Aged and Disabled (Medicare), under Title XVIII of the Social Security Act, is a program providing for persons who are aged or disabled, but no provision is made for the individual who is in double jeopardy of being aged and handicapped. This group of the elderly requires equitable treatment under the program: the dependence caused by age are aggravated by the special problems arising from incapacitation.

The Federal health care programs benefiting the elderly include health resources development construction and modernization of facilities, construction of nursing home and intermediate care facilities, and grants to States for medical assistance programs (Medicaid). These programs are structured to meet the needs of the mainly able-bodied elderly, and if the impaired elderly are included in the implementation of these programs they will provide significant improvement in the lives of thousands of aging handicapped persons. The Comprehensive Employment and Training Act (CETA), 1973, funds can be used to expand the employment of the handicapped elderly. Special appropriations should be clearly designated for the handicapped, including the handicapped elderly.

Housing

Based on the 1970 Census, 3.8 million elderly households (head 65 and over) rented their residences in 1969. An estimated 2 million persons paid at least thirty-five percent (35%) of their income for rent. In 1970. over 6 million elderly homeowners paid an average of eight point one percent (8.1%) of their home in property taxes. Households with incomes of less than $2,000 paid property taxes amounting to an average of sixteen point six percent (16.6%) of their incomes. Taxes were much higher (as high as 30%) in certain regions of the nation. The handicapped elderly constitute a significant number of the elderly homeowners. In 1974, the average homeowner (of all ages) paid about three point four percent (3.4%) of his income in property taxes.

There are housing programs designed for the elderly and the handicapped by the Federal Government but the lumping together of the elderly and the handicapped in the appropriation of funds for these housing projects creates a situation in which the double jeopardy of being elderly and handicapped is not addressed. There should be defined appropriations for the construction of housing units for the handicapped elderly. Such units should include space for "essential persons" looking after the handicapped: the present practice of dealing with housing units for the handicapped elderly within the general appropriations for the elderly does not go far enough in solving the problems of this special group.

Income Maintenance

The Federal Bureau of the Census reported that in 1974 the following proportion of unrelated individuals aged 65 and over were below the poverty level: 28.9% for whites, 60.5% for blacks, but 31.8% for all ethnic groups considered. For families of the elderly. 7.7% for whites, 27.7% for blacks and 9.5% for all races below the poverty level. For the handicapped elderly as a group, the income situation is worse. Their poor condition is the root of most complaints and dissatisfaction expressed by the aged in the United States. Income maintenance for the older Americans should not be studied and evaluated from only the racial point of view, but also from the point of view of the severity of their physical and mental conditions in old age. It is important that the income of the able-bodied elderly be compared with that of theimparied elderly in assessing the performance of federal income maintenance programs for the elderly.

Legislative matters dealing with the income of the elderly requires a thorough study of the existing sources of income for the American elderly. The sources of income vary for different racial groups in the country, but Social Security remains the principal source of income for all the groups as can be observed from Table 7. Attention should also be given the income problems of the impaired elderly. The Supplemental Security Income program should provide additional funds for the persons who are not only aged but also handicapped. Income derived from wages is the second most important source for older people and this is the source in which the handicapped are least represented. The third ranking income source is income derived from assets in real estate interest, dividends and other investments. Public assistance is the fourth ranking income source for elderly people.

SEARCH FOR SOLUTIONS

The 1971 White House Conference on Aging held Special Concerns Sessions on the handicapped aged. The purpose of these special sessions was to provide for in-depth discussion on special aspects of the circumstances of the older population of the blind, deaf and physically disabled.

The recommendations of the Conference for the blind included that the National Eye Institute be required to better statistics on incidence, prevalence, and etiology of blinding eye conditions; that Congress amend Titles XVIII and XIX of the Social Security Act to cover low vision aids when the need is certified by an ophthalmologist or an optometrist specializing in low vision treatment; and that the number of low vision centers be increased and staffed under the supervision of an ophthalmologist or a qualified optometrist. It was further recommended that the Administration and Congress develop a network of personal care benefits for individuals with a certain level of functional disability to enable the other person to purchase whatever services are necessary to help him remain in his own home, if he so wishes; such benefit is to be in addition to basic minimum income and assure a financial basis for local community service providers. For the deaf and physically handicapped, there are other recommendations for what Federal, State and Local agencies should do to enhance their rehabilitation.[5]

The problem with the treatment of handicapped elderly within the Federal and State aging programs is that the appropriation process does not designate specific funds for this group of older Americans. The advocacy groups of all races working for the aged paint the pictures of the handicapped elderly to push legislation through Congress. However, the legislation and Federal appropriations that result, do not designate specific line items for the impaired elderly. The field of aging may not be short of ideas about what should be done for the handicapped elderly, but the aging programs and legislation at Federal and State levels do ignore this special group. Any action that would provide a better future for the impaired elderly within the aging programs should aim at carving

Table 7. Elderly: Proportion with Incomes from Specified Sources, 1974

Sources	Families			Unrelated Individuals		
	All %	White %	Black %	All %	White %	Black %
Earnings	53.29	52.1	63.3	19.0	19.0	19.4
Income–Other Earnings						
1. Public Assistance	7.5	5.2	30.9	10.5	8.9	28.4
2. Social Security	90.7	91.4	84.5	89.1	90.1	78.7
3. Other Transfer Income[4]	18.5	18.7	15.0	14.3	14.4	14.3
4. Other Unearned Income[5]	65.9	70.2	23.8	56.4	60.0	15.7

SOURCE: Bureau of Census figures obtained through Congressional Research Service.

out *special defined appropriations* for the handicapped elderly. The following recommendations should be of special interest to those who are working to make the existing Federal programs for the elderly more meaningful for the impaired elderly:

1. Handicapped persons with special skills irrespective of age should be allowed to remain actively employed without means test (retirement test) within the Social Security System.
2. An increased number of handicapped elderly should be considered for employment under Title IX of the Older Americans Act of 1965, and the Comprehensive Employment and Training Act, 1973. Provisions should be made in the Federal budget for direct appropriations for the handicapped elderly under these Acts.
3. The Supplemental Security Income Program (SSI) of the Social Security Act (Title XVI) should be amended to provide special income maintenance for any person who is both aged and handicapped.
4. Provisions should be made in the Housing Act of 1959, as amended, (Section 202) and the Housing Act of 1949, as amended, (Section 521 and 525) to provide for direct appropriation for projects serving only the handicapped elderly.
5. Special legal services should be guaranteed to the mentally impaired elderly within the Older Americans Act. The legal problems of the mentally impaired elderly should be distinguished from those of other elderly.
6. The elaborate training provisions of Title IV of the Older Americans Act should be redesigned to provide specifically for the inclusion of facilities for students specializing in the problems of the handicapped elderly as part of multi-disciplinary centers of gerontology, and personnel training.

A significant development favoring the handicapped elderly is the reference in the 1975 Federal Council on Aging, *Annual Report to the President*, to "frail elderly" defined as:

> ". . . the elderly—usually the oldest of the old—who require support from society because of disabilities of increasing age"

The Report called for "some needed national actions" which would provide a national system of care for the group of elderly. It is premature to see this as a new awareness for special treatment of the handicapped, but it provides some satisfaction to know that certain persons are starting to speak out for this neglected segment of our population.

SUMMARY

Inspite of the lack of data available on the handicapped elderly, we have made an effort to provide quantitative information about this population group. Their place in Federal programs serving the elderly was reviewed and found to be minmal. It was maintained in all programs (health, housing, income maintenance and employment) that the handicapped are not appropriated their fair share. The impaired elderly are used by advocacy groups to convince law-makers to approve funds, but in the final slicing of the cake the special needs of the handicapped elderly are not properly addressed. We referred briefly to the work of the 1971 White House Conference on Aging in the area of the handicapped elderly and stressed that the basic aging issue is not one of ideas about the needs of handicapped elderly but the translation of ideas into *defined provisions in legislation and in the Federal budget without grouping them with all the rest of the able-bodied elderly population.* Finally, we made a number of specific recommendations for amendments in the Social Security Act, the Housing Act, and the Older Americans Act to provide for *defined coverage* of the handicapped elderly.

REFERENCES

1. Social Security Legislation, 1935
2. This is a conservative estimate of the handicapped elderly based on Department of Health, Education and Welfare publications of Social Security Disability payments statistics and vital and health statistics.
3. *Developments in Aging, 1974, and January–April, 1975.* A Report of the Special Committee on Aging, United States Senate, June 24, 1975 (p. xix)
4. RILEY, Matilda W. and FONER, Ann, *Aging and Society, Vol. I, An Inventory of Research Findings.* (New York: Russell Sage, 1968) p. 309.

5. 1971 WHITE HOUSE CONFERENCE ON AGING, *Recommended for Action, Disability and Rehabilitation*. Washington, D.C., 1971 (p. 8)
6. Federal Council on the Aging, *Annual Report to the President–1975*. Washington, D.C. (p. 6)

SELECTED BIBLIOGRAPHY

U.S. Department of Health, Education and Welfare, *Older Americans Act, 1965, as Amended and Related Laws*. DHEW Publication No. (OHD) 75-20170 Washington, D.C., December, 1975.

United States State, *Developments in Aging*, June 24, 1975.

U.S. Department of Health, Education and Welfare, *Social Security Disability Applicant Statistics, 1970*–published 1974.

U.S. Department of Health, Education and Welfare, *Acute Conditions: Incidence and Associated Disability, United States, July 1973–June, 1974*. National Center for Health Statistics, Rockville, Md., 1975.

1971 WHITE HOUSE CONFERENCE ON AGING, *Reports of the Special Concerns Sessions on Aging and Blindness, Physical and Vocational Rehabilitation of Older People, and Reports on Aging and Deafness.*

U.S. Department of Health, Education and Welfare, *A Summary of Selected Legislation Relating to the Handicapped, 1974*. Washington, D.C., May, 1975.

Confidence Games Against the Elderly, Hearing of the Select Committee on Aging, U.S. House of Representatives. Held in New York, January 13, 1976.

BUTLER, Robert N., *Why Survive in America? Being Old in America*. Harper & Rowe (N.Y., 1975).

First National Conference on Aging and Blindness, Proceedings of the Conference held April 24–26, 1975 on "Meeting the Challenges of Elderly Persons with Sight Difculties, Action '75".

U.S. Department of Health, Education and Welfare, *Federal Assistance for Programs Serving the Handicapped*, DHEW Publication No. (OHD) 76-22001, Washington, D.C., 1976.

Congressional Research Service, *Federal Responsibility to the Elderly* (Executive Programs and Legislative Jurisdiction). Charts compiled for Select Committee on Aging, Washington, D.C., 1976.

United Nations, *Aging: Trends and Policies*, United Nations, N.Y., 1975.

Federal Council on Aging, *Annual Report to the President–1975*, Washington, D.C., 1976.

ATCHLEY, Robert C., *The Social Forces in Later Life: An Introduction to Social Gerontology*. Wadsworth Publishing Co., Calif., 1972.

RILEY, Matilda and FONER, Ann, *Aging and Society, An Inventory of Research Findings*. (New York: Russell Sage, 1968).

☆ U. S. GOVERNMENT PRINTING OFFICE : 1977 232-034/6199

HV1775 c.1
W587 THE WHITE HOUSE CONFERENCE
Vol. I ON HANDICAPPED INDIVIDUALS,
WASHINGTON, D.C., MAY 23-27, 1977.
VOLUME ONE: AWARENESS PAPERS.
(1977)

Date Due

HV1775 c.1
W587
Vol. I
THE WHITE HOUSE CONFERENCE ON
HANDICAPPED INDIVIDUALS, WASHING-
TON, D.C., MAY 23-27, 1977.
VOLUME ONE: AWARENESS PAPERS.
(1977)

DATE	ISSUED TO
	Reference Copy

AMERICAN FOUNDATION FOR THE BLIND
15 WEST 16th STREET
NEW YORK, N.Y. 10011

Printed in U.S.A.